

## THESIS / THÈSE

### MASTER IN BIOMEDICINE PROFESSIONAL FOCUS

A pilot study to compare two data collection methods to elicit information about patients' experience with Crohn's disease

#### Face-to-face interviews versus social media research

Vandersteen, Isabelle

*Award date:*  
2020

*Awarding institution:*  
University of Namur

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**Faculté de Médecine**

**A PILOT STUDY TO COMPARE TWO DATA COLLECTION METHODS TO ELICIT  
INFORMATION ABOUT PATIENTS' EXPERIENCE WITH CROHN'S DISEASE: FACE-  
TO-FACE INTERVIEWS VERSUS SOCIAL MEDIA RESEARCH**

**Mémoire présenté pour l'obtention  
du grade académique de master en sciences biomédicales**

**Isabelle VANDERSTEEN**

**Août 2020**

**Université de Namur**  
**FACULTE DE MEDECINE**  
Secrétariat des départements  
Rue de Bruxelles 61 - 5000 NAMUR  
Téléphone: + 32(0)81.72.43.22  
E-mail: manon.chatillon@unamur.be - <http://www.unamur.be/>

**A pilot study to compare two data collection methods to elicit information about patients' experience with Crohn's disease: face-to-face interviews versus social media research**

VANDERSTEEN Isabelle

Abstract

**Background:** Qualitative research is widely used in the medical field, because it allows capturing experiences, priorities, needs and perspectives of the patients. In its very recent guidance on Patient – Focus Drug Development: Methods to Identify What Is Important to Patients: Guidance for Industry, Food and Drug Administration Staff, and Other Stakeholders, Guidance (June 2020), FDA mentions both face-to-face patient interviews and social media research as methods used to capture patients experience data. But limited data is available that compare these two methods and there is a need to determine if social media research can be used as a valid method to elicit relevant patient information.

**Aim:** The objective of this study is to compare the reliability, validity and relevance of the data collected through patient face-to-face interviews versus social media research to determine if social media research allows to validly capture relevant patients' information in a Crohn's disease population. More specifically, the number of concepts and the level of detail used to describe each concept (symptom, impact and treatment) will be assessed for both methods. The hypothesis of this research is that social media research also allows highlighting reliable, valid and relevant information as patient's face-to-face interview.

**Methods:** First, a literature review has first been done to compare the two data collection methods, in any conditions. Then, patient face-to-face interviews and social media research have been compared by collecting information about Crohn's disease patients through these two methods. Data has been analysed using ATLAS.ti, a qualitative software. The data were sorted, organized and sort into three categories: symptoms/signs, impacts and treatments.

**Analysis:** Social media had reported a total of twenty-nine concepts, including fourteen symptoms, four signs, six impacts, five treatment-related concepts. And patients interviewed had reported a total of thirty-five concepts, including twenty symptoms, six signs, eight impacts, six treatment-related concepts.

**Conclusion:** Social media research allows to collect relevant and correct information. And information collecting through face-to-face patients' interview is more specific, detailed and comprehensive. But it is more time consuming. For a global understanding of the disease burden, treatment expectation, social media could be enough to guide research questions and treatment development.

**Keywords:** interviews; social media research; qualitative research; online; Crohn's disease

Mémoire de master en sciences biomédicales  
Août 2020

**Thesis Supervisor: Prof. Laure Delbecque and Prof. Martin Desseilles**

## Table des matières

List of Abbreviations .....	4
1. Introduction .....	5
1.1. Literature review.....	6
1.2. Study on Crohn's disease .....	9
1.2.1 The disease and symptoms.....	10
1.2.2. Challenges and effect on quality of life .....	11
1.2.3. Main treatments .....	12
2. Study Objectives .....	14
3. Methods.....	15
3.1. Study design .....	15
3.2. Ethical committee .....	15
3.3. Study population.....	15
3.4. Identification of the social media .....	15
3.5. Patients' face-to-face interview.....	16
3.5.1. Patient eligibility and recruitment .....	16
3.5.2. Interviews.....	17
3.6. Preparation for the analysis.....	17
3.7. Analysis .....	18
4. Analysis .....	20
4.1. Social media .....	20
4.1.1. Study population.....	20
4.1.2. Symptoms/Signs of Crohn's disease .....	20
4.1.2. Impacts of Crohn's disease .....	23
4.1.3. Treatments of Crohn's disease .....	28
4.2. Patient interviews .....	28
4.2.1. Study population.....	28
4.2.2. Saturation.....	29
4.2.3. Symptoms/Signs of Crohn's disease .....	30
4.2.4. Impacts of Crohn's disease .....	33
4.2.5. Treatments of Crohn's disease .....	37
5. Conclusions and perspectives .....	40
5.1. Number of concepts (primary objective).....	40
5.1.1. Symptoms/Signs of Crohn's disease .....	40
5.1.2. Impacts of Crohn's disease .....	43
5.1.3. Treatments of Crohn's disease .....	44

5.2. Level of detail.....	46
5.3. Language used .....	46
5.4. Study population.....	47
5.5. Time .....	48
5.6. Perspectives .....	48
6. Acknowledgments.....	51
7. References .....	52
Annexe 1: Case Report Form (CRF) .....	56
Annexe 2: Interview guide .....	57
Annexe 3: Coding Book .....	63

## List of Abbreviations

Abbreviation	Definition
CHU	Centre Hospitalier Universitaire
CRF	Case Report Form
DHIF	Demographic and Health Information Form
EMA	European Medicines Agency
FDA	Food and Drug Administration
GI	Gastrointestinal
GP	General Practitioner
IBD	Inflammatory Bowel Disease
Int	Interview
ORL	Otorhinolaryngology
PRO	Patient-Reported Outcomes
RCHU	Recto-colite ulcéro-hémorragique
SMR	Social Media Research

# **A pilot study to compare two data collection methods to elicit information about patients' experience with Crohn's disease: face-to-face interviews versus social media research**

## **1. Introduction**

Over time, health care has evolved from a paternalistic model to a patient-centred model where the patient is treated as a unique individual (Pelzang, 2010). There the patients' needs and preferences are discussed with the patients and the health care professionals (Epstein & Stree, 2011). These discussions offer important information about the disease and treatment burden that only the patient can provide (Lavallee, Chenok, Love, Petersen, Holve, Segal & Franklin, 2016). Patient-centric information can be useful in a real-world setting to help the treatment decision-making process or improve the communication between patients and health care professionals, but can also support the drug development process to assess the safety and efficacy of a medical product (e.g., develop relevant endpoints based on patient-reported outcomes ; provide information about treatment preferences, risks and burdens; find better strategies of patients' recruitment in a clinical trial). (Lavallee and al, 2016 ; Patrick and al 2007 ; Academy of Managed Care Pharmacy, 2018; Food and Drug Administration, 2018; Bredart, Marrel, Abetz-Webb, Lasch & Acquadro, 2014).

Experiences, priorities, needs and perspectives of the patients can be captured through qualitative studies. In qualitative studies, the research query is understood, using a humanistic or idealistic approach. People belief's, experiences, behaviour or interaction can be understood thanks to qualitative methods (Pathak, Jena and Kalra, 2013). According to the FDA (2019), they are many qualitative methods that can be used to collect patients' information such as face-to-face interviews (Int), focus group interviews, advisory boards, and public meetings. Recently, the FDA encourages researchers to also explore the use of social media research (SMR) to capture relevant patients experience data. Each method has its strengths and weaknesses. The choice of the most appropriate methods depends on several criteria, including the research question (FDA, 2020)

In this pilot study, we will compare two methods used to explore patients experience data: face-to-face patients' interview and social media research.

Face-to-face patients' interview is based on a verbal discussion between an interviewer (i.e., the researcher) and an interviewee (e.g., the patient or caregiver) aimed at eliciting relevant information, in relation with a specific purpose. The topics are controlled by the interviewer, based on a semi-structured interview guide, but the interviewee is free to answer (or not) the open-ended questions. Interviews are audio-recorded, transcribed and analysed using qualitative research software (Bredart, 2014). One of the main strengths of patients' interview is that the researcher has access to the health and demographic information of the interviewee (such as exact diagnosis, potential comorbidities, treatment, age, gender, ...), because most of the time recruitment is done through clinicians. Another strength is the professional relationship built between the interviewer and the interviewee that allows to create a climate of confidence so that patients are willing to explain their stories. In cases where something is not clear enough, interviewer can ask for few more details. However, this method can be time consuming and expensive. Indeed, it can take a lot of time to recruit patients and interview them. Also, the interview itself can be a burden for some participants. Finally, the sample size

for the interview will be small. So, with this method, the representativeness of the study population can be questionable.

Nowadays, social media is one of the main means of communication. They are platforms to share opinions and ideas between large communities of people, including patient communities. The most common social media are Facebook, Twitter and YouTube (Branthwaite & Patterson, 2011). Today, there is a growing number of social media users, posting messages, videos or pictures. All their posts generate the content of information that can be analysed in a social media research (Snelson 2016). It consists in extracting and analysing data found on any social media, such as forums or blogs. One of the main advantages of social media research is that it is expected that the study will be faster and cheaper. However, there is no interaction between the social media users and the researcher. So, if patients' stories are not complete or not clear, there is no possibility to ask for further details. The representativeness of the population is also quite difficult to assess as users' information may not be available or cannot be checked for accuracy. More, there is no certainty that social media users are truly diagnosed patients. On the Internet, nobody knows who is behind the screen. Are they real patients? What is their exact diagnosis? Is there any comorbidity associate to their disease? Despite these weaknesses, social media research begins to be used in the medical field, for example, in pharmacovigilance to determine the safety of a drug once it is on the market or to find meaningful information about patients' experiences (McDonald, Malcolm, Ramagopalan & Syrad, 2019).

In its very recent guidance on Patient –Focus Drug Development: Methods to Identify What Is Important to Patients: Guidance for Industry, Food and Drug Administration Staff, and Other Stakeholder, Guidance (June 2020), FDA mentions both face-to-face patient interviews and social media research as methods used to capture patients experience data. However, limited data is available that compare these two methods and there is a need to determine if social media research can be used as a valid method to elicit relevant patient information.

Lastly, questionnaires for patient-reported outcomes (PRO) are written using the patients' lingo. Generally, patients' interviews could be used to have a better understanding of the language used by patients (European Medicines Agency, 2018). Maybe the input of social media can also be useful for it.

### 1.1. Literature review

A literature review has been conducted to explore if comparisons of patient's face-to-face interview and social media research have already been performed across several conditions.

To elicit relevant articles, two databases have been used: Pubmed and Google Scholar. Search, terms used were: (i) 'patient reported outcomes', (ii) 'social media', (iii) 'forum', (iv) 'blog', (v) 'social media research', (vi) 'patient interview', (vii) 'qualitative research', (viii) 'online qualitative research', (ix) 'face-to-face interviews' and (x) 'patient forum reported disease'.

Based on these search terms, the total number of hits was 66. A preselection of relevant articles has been done based on the title and the abstract of each article, using inclusion and exclusion criteria (see Table 1). Only articles that compare the two qualitative methods have been kept. From the 66 articles, only 16 articles have been kept.



To ensure that all relevant studies are included in the literature review, hand-searching has been done. References of the 16 articles have been screened. Two more articles have been found.

In total, 16 articles were deemed relevant and have been used for the literature review.

**Table 1: Eligibility criteria for targeted literature review**

<b>Criteria</b>	<b>Include</b>	<b>Exclude</b>
Population	Adult	Children
Intervention	No restrictions	No restrictions
Study settings	Qualitative study: comparison between the two methods	Any other study types
Publication language	English	Not English
Date of publication	1999 – Present	Any studies prior to 1999

After reading those documents, some topics have been highlighted, analysed and discussed. The main differences found in the literature between the two methods are summarised in Table 2.

First, in both methods, study populations are expected to be different. Indeed, social media research has the power to approach patients that are isolated or not able to go to an interview. However, the sample population from social media is unknown (no specific demographic and health information available). More, there is a risk of fake profiles: anonymous texts or pseudonyms are frequent on the Internet and fake profiles could be hidden behind them. (Seale, 2010 ; McKennaa, Myersb & Newman, 2017). On the opposite, in the face-to-face interview method, all the participants have been recruited based on inclusion and exclusion criteria. So, the study population (e.g., health and demographic information) is well known to the researchers (McDonald, 2019). Despite all, with the emergence of the new technology and a growing number of social media users, the sample size in social media research is generally larger than for the patient interviews (Seale, Charteris-Black, MacFarlane & McPherson, 2010). Also, in qualitative interview the sample size is calculated using the concept of saturation (Food and Drug Administration, 2009).

Secondly, differences in the discourse of the patients during an interview and on social media could be expected. During an interview, interviewer can notice paralinguistic cues of participants. Paralinguistic cues embrace all the non-verbal. All the hesitations, repetitions, laughs, smiles or tears, etc. can be analysed by the interviewer (Seale, 2010; Synnot, 2014). All those paralinguistic cues are missing in social media research. However, textual cues can be used instead. Those textual cues can be the use of capital letters, emoticons, abbreviations, etc. (Synnot 2014). Without the paralinguistic cues, some nuances of the language are missing. So, the interpretation of the patients' feeling can be problematic (Seale, 2010).

Then, in qualitative research, researchers must deal with a large amount of information. Because of the emergence of technologies and particularly due to the huge number of social media users, the volume of data in social media research can be much higher than data collected during patients' interviews (McKennaa, 2017). In this huge amount of collected data, some information is more relevant. But is there less noise in the interview or in social media research? Researchers do not fully agree on this. According to Synnot (2014), discussions on online

forums contain less noise than patients' interview. Indeed, they noticed that patients' answers are shorter on social media. On the other side, patients tend to explain in detail their stories, providing a lot of data, during interviews. Sometimes, stories shared by the patients are not relevant to the question asked (Synnot, 2014). In contrast, according to McDonald (2019), the real stake of social media research is to elicit relevant information in the huge amount of data collected. To avoid noise in the discourse of the participants, it is possible to refocus the discussion, during an interview.

**Table 2: Summary of the differences between patients' interview and social media research**

	<b>Patient's interview</b>	<b>Social media research</b>
Study population	-Small sample size (saturation) -Well-known study population (inclusion/exclusion criteria)	-Higher sample size -Difficulties to obtain patients' health and demographic information and risk of fake profiles
Language analysis	Paralinguistic cues	Textual cues
Volume of data and noise in the discourse	- Less amount of data - Sometimes patients shared stories that do not answer the asked question	-Huge amount of disorganised data - Short answer but in a huge amount of disorganised data
Content and details	-If needed, opportunity to ask for more details	-Discussions are fixed: no opportunity to ask for more details -Emergence of new themes -Greater level of detail especially for sensitive stories
Origin of data	-Data is generated by interviewer, by asking questions -Topics chosen by the interviewer	-Data are self-generated by the discussion between social media users -Topics chosen by the users
Time and costs	More time and costs	Less time and costs
Ethical perspective	-Anonymity protects the participants -Malfeasance can be minimised by interviewer	-Anonymity of participants is not always possible -Risk of patients' stigmatisation

Fourthly, through his study, Synnot (2014) has shown that all the topics raised in interviews were also raised in social media research. But, generally, additional topics were raised in social media research. For example, in social media research, a new theme emerges: support and mutual aid. At the same time, patients share their experiences, their treatment, their solutions and their support to others who live in the same experiences. Obviously, that kind of information is not found in a face-to-face interview. In addition, it has been determined that the level of detail is greater in social media research than in patients' interview, especially for sensitive stories (Seale 2006 ; Seale, 2010). However, the advantage of interviews against

social media research is the interaction between the researcher and participants. During a face-to-face patients' interview, if researchers need more explanation about a topic, he has the opportunity to ask more detail to participants (Seale, 2010).

In addition, topics discussed are generated differently, in both methods. During patients' interview, interviewer generates the discourse of the patient thanks to open-ended questions. Rather, social media users generate the debate and choose topics that they consider important for them: own experiences with disease or treatment, solutions they found against pain, etc. Sometimes, topics could be considered as marginal experiences of disease for the researchers, but patients discussed a lot about it on forums (Seale, 2010). So, in case of social media research, researchers have less control on the data than in the interview (McKenna, 2017).

Additionally, one huge advantage of social media is the immediate accessibility of the data. All information about patients' experience is already available on the Internet. This allows beginning as quickly as possible a study (Zwaanswijk & Van Dulmen 2014). Also, social media research is cheaper than face-to-face patients' interview. Indeed, some costs can be cut in this kind of research such as interviewer's travelling expenses, hiring rooms for the interview, compensations for the patients, etc. The most part of the research can be done in the office of the researcher (Murgado-Armenteros, Torres-Ruiz & Vega-Zamora, 2012). These are examples of how social media can be cost saving and time saving in relation to collecting relevant information through patients' interview.

Finally, ethical considerations have to be in the centre of social media research. Currently there is no real guideline for social media research. Technologies evolved too quickly, so a guideline will be invalidated when new technologies come on the market (Hunter, 2018). The privacy and identity of all the participants have to be preserved. More, harm and emotional distress have to be avoided. This could be a real challenge for the researcher. To avoid it, it is important to understand the evolution of technologies and to be prepared, for example by doing a strong protocol (Rhodes, 2003 ; Hunter, 2018).

To conclude with the literature, social media research is expected to be substantial. However, this method is preferably used for large questions of research. Indeed, the huge amount of disorganised data could make the analysis very difficult (Seale, 2010).

## 1.2. Study on Crohn's disease

For this study, Crohn's disease has been selected for three main reasons. First, according to the European Medicines Agency (EMA), there is a need of patients' input to have a better understanding of the disease burden (symptoms and impacts). In addition, the primary endpoint in Crohn's disease trials should be the co-primary evaluation of symptomatic remission and endoscopic remission (European Medicines Agency, 2018). Symptomatic relief should be evaluated by patient-reported outcomes (PRO) and the EMA guideline recommends the development of new PRO to be used as co-primary endpoint in Crohn's disease trials. In this context, it is interesting to analyse which methods is the best to collect patients' input to develop this new PRO (European Medicines Agency, 2018).

The second reason is the age of the population suffering from Crohn's disease. Indeed, the incidence of this disease is increasing among young people. Generally, the onset of Crohn's disease begins around the age of 15 years. The peak of incidence is between 20 and 34 years (Lynch & Spence, 2008). In studying a disease that affects a young population, it is expected to have a lot of information from patients on social media.

The last reason to focus on Crohn's disease is the incidence of the disease in Belgium. Approximately 20 000 patients have been diagnosed with Crohn's disease in Belgium (MICI). Calculated from the Belgian population, Crohn's disease patients represented 1 person on 550.

To have a better understanding of the disease, some information can already be found in the literature. This information is helpful to create an interview guide and to have a better understanding of the experiences, priorities, needs and perspectives of the patients.

### 1.2.1 The disease and symptoms

Crohn's disease is a chronic inflammatory bowel disease. Any part of the gastrointestinal tract could be affected, as shown in the Figure 1. However, the most common affected site is the ileum. The symptoms of the disease are evolving, patients live with periods of remissions and relapses. The progressive nature of the disease could lead to bowel damage and disability (Torres, Mehandru, Colomber & Peyrin-Biroulet, 2017 ; Gracia-Sanjuan, Lillo-Crespo, Richart-Martinez & Sanjuan Quiles, 2018).



**Figure 1: parts of gastrointestinal tract mostly infected by Crohn's disease**

It is supposed that this disease is resulting from the interaction between the genetic susceptibility, environmental factors and intestinal microflora. Symptoms of the disease are caused by an abnormal immunological response in the intestine. Moreover, it appears that the epithelial barrier function is altered (Torres, 2017).

Clinical presentation depends on disease location, severity of inflammation, and disease behaviour. Symptoms of this disease are heterogenous and sometimes there are insidious. There is a correlation between the clinical presentation and the disease location severity of the inflammation and disease behaviour. Nevertheless, at the physical examination, patients present typically abdominal pain, chronic diarrhoea, weight loss and fatigue. Anorexia is also common for patients affected by Crohn's disease. Further, some patients present rectal bleeding

and bloody diarrhoea. Sometimes, patients suffer complications: septic complications, perianal diseases, skin, joints or eyes extra-intestinal manifestations. Perianal disease could be skin lesions (ulceration and skin tags), anal canal lesions (stenosis, fissures and ulcers) and fistulas with or without abscesses (Torres, 2017).

Crohn's disease can be classified into mild, moderate or severe. Not only the classification depends on the clinical symptoms (presence of malnutrition, systemic toxicity, abdominal mass, obstruction, degree of weight loss, etc.), but also on the response to treatment (Torres, 2017).

### 1.2.2. Challenges and effect on quality of life

The quality of life is impaired by the Crohn's disease. Patients suffering from this disease faced a lot of challenges. The three main challenges are the symptoms, all the tests that they must do and the treatments. Three major categories of issues resulted from the disease's symptoms: physical, social and emotional (Lowe, Kenwright, Wyeth & Blair, 2012).

The physical condition of the patient can be altered. Due to bowel urgency and poor absorption in the intestine, patients can lose weight dramatically. This weight loss is commonly accompanied by nutritional deficiency (Lynch, 2008). Sometimes, patients can also suffer from starvation and/or dehydration (Carlsson & Persson, 2015).

Crohn's disease has a huge emotional and psychological impact on the patient. Stress and anxiety are an integral part of daily life. Symptoms are stressful for the patients. Sometimes, due to bowel urgency, they must find as quick as possible toilets. Patients also feel humiliation and embarrassment about their condition. This feeling leads impression of helplessness and isolation. Sometimes, the stress can also lead to anger and frustration. Commonly, patients affected by Crohn's disease, also suffered from depression. This depression is often associated with anger and powerlessness (Lynch, 2008).

Because of the possible changes in their appearance, patients, mainly young patients, feel different from the others (Lowe, 2012). Most of the patients do not recognise themselves in the mirror, in comparison with the person they were before the diagnosis of the disease (Gracia-Sanjuan, 2018).

Patients living with Crohn's disease feel fear because of all the things they did not know about it. Patients do not fully understand all the implications of this disease. They created a self-protection to cope with the unknown of the disease (Carlsson, 2015). First, frequently patients must live with their symptoms, a long time before having a diagnostic. They are frightened to have something worse than Crohn's disease. Second, when the diagnosis is done, patients must accept their disease. They often experience the "why me" (Lynch, 2008). Third, there is a lack of reliable information for the patient. They learn every day about their disease to become an expert in their condition (Carlsson, 2015).

Socially, patients feel isolated due to their disease. This feeling is higher among youth (Lynch, 2008). They feel shame about their disease and feel that they are socially stigmatised because of the abdominal bloating and the bowel urgency (Gracia-Sanjuan, 2018). At school, patients must sometimes miss school and examination. At university, some patients live with other students. Sharing bathroom is another challenge that they must face. Patients live similar

experiences at work. They must share a bathroom with colleagues and sometimes must miss work to rest or for their treatment (Lynch, 2008).

However, patients reported all the support they receive from their family and their friends. This support is given by the most intimate circle to help patients to cope with the disease. This means for the daily life tasks or when the patients are in hospital (Gracia-Sanjuan, 2018; Lynch, 2008).

The intimate relationship of the patient can also be altered. The parenthood is also a challenge for the patient. Women experienced complications during the pregnancy. Patients reported that the first pregnancy experience is so difficult that they give up the idea to have a second child (Gracia-Sanjuan, 2018).

As said before, patients suffering from Crohn's disease must be monitored. Patients must do a lot of tests to see the evolution of the disease. The most common test is the colonoscopy (Torres, 2017). A big issue is the costs related to those tests and physicians they must see to do it (Lynch, 2008).

Treatments are prescribed not only to control symptoms but also to monitor the daily tasks (Gracia-Sanjuan, 2018). There are several treatments for this disease including pills or surgery. Patients must often try a lot of different medication before finding the most appropriate drug for the patient or before having surgery. Patients reported a high number of adverse events (Lynch, 2008). Surgery consists in resection of a small length of the bowel or in ostomy. This surgical act consists of creating an opening in the bowel to eliminate the body waste (Carlsson, 2015). Plus, patients generally see a dietitian to have a specific alimentation and to compensate nutritional deficiencies (Lynch, 2008). Finally, patients reported that all the treatments, pills and other tubes, are a reminder of the disease (Lowe, 2012).

A last challenge for the patient is the contact with healthcare professionals. Generally, patients completely trust the physician that diagnose them, because the physician gives them an answer to their questions. Thereafter, patients feel that healthcare professionals do not give all the answers to their questions and do not give them all they need (Gracia-Sanjuan, 2018, Lynch, 2008).

### 1.2.3. Main treatments

Currently, Crohn's disease cannot be cured. With the treatments, symptoms can be controlled or reduced. Main treatments are medicines, but the surgery can sometimes be needed (NHS, 2018). Diet and lifestyle changes can also help to manage symptoms of the disease (Westphalen, 2020).

There are many drugs that can be given to the patient. Most common drugs for the treatment of Crohn's disease are corticosteroids, salicylic derivatives, immunosuppressants or biological. Drugs are selected based on the severity of the disease and the response to previous treatments (Torres, 2017). More, what works for one patient do not necessarily work for another: the treatment of Crohn's disease is very personalised for each patient (Westphalen, 2020).

Each treatment has its specific mode of action against the Crohn's disease. For instead, they can reduce the inflammation that had taken place in the patients' bowels, reduce the immune response induce by the disease, or they can combine both modes of action. Also, by taken these medications, patients could suffer from side effects. Here are few examples: swelling, weight

gain, nausea, vomiting, headaches, acne, indigestion, high blood pressure, changes in the mood, higher risk of infection, etc. (NHS, 2018 ; Westphalen, 2020).

Both, the mode of action and side effects for each class of medication are summarised in the table below (Table 3).

**Table 3: Summary of Crohn's disease treatments (NHS, 2018 ; Westphalen, 2020)**

<b>Treatment</b>	<b>Action</b>	<b>Side effects</b>
Corticosteroids	Reduce inflammation and reduce immune response	Swelling, weight gain, acne, indigestion, high blood pressure and also in the eyes (glaucoma), changes in the mood, higher risk of infection and slower growth in children.
Salicylic derivatives	Reduce inflammation	Nausea, vomiting, heartburn, diarrhoea, headache
Immunosuppressants	Reduce immune response	Headache, nausea, vomiting, higher risk of infection and liver problems
Biological	Reduce inflammation	Headaches, fever, chills or low blood pressure
Surgery	Remove the damaged part of the intestine	Diarrhoea, bleeding in the belly, intra-abdominal abscess, incisional hernia, short bowel syndrome, intestinal blockage formed by scar tissue, dehiscence, or anastomosis

## **2. Study Objectives**

The primary objective of this pilot study is to compare the reliability, validity and relevance of the data collected through patient face-to-face interviews versus social media research to determine if social media research allows to validly capture relevant patients' information in a Crohn's disease population. More specifically, the number of concepts (i.e., symptoms, impacts and treatment burden) and the level of detail used to describe each concept (e.g. duration, frequency and severity of symptoms) will be assessed for both methods. The hypothesis of this research is that social media research also allows highlighting reliable, valid and relevant information as patient's face-to-face interview.

The secondary objective is to compare the language (e.g., words, expressions, examples) used by the patients to describe their disease/treatment across the 2 qualitative methods. This is important to know for the development of new PRO instruments that aims to include the exact terminology used by patients to describe their disease.

Finally, the amount of time needed to conduct the study will be compared: is social media research less time consuming than patients' face-to-face interview?



### **3. Methods**

#### **3.1. Study design**

This is a qualitative, observational study that consists in in-depth, one-on-one interviews with patients who had a diagnosis of Crohn's disease and social media research. These two methods have been used to collect information about Crohn's disease patient experience with their disease and treatments. These two methods will be compared in terms of reliability, validity and relevance of the data collected.

#### **3.2. Ethical committee**

To perform this study, protocol and annexes have been submitted to the ethical committee of Centre Hospitalier Universitaire (CHU) Mont Godinne, at the end of last summer. In the annexes, the Informed Consent Form (ICF), the Case Report Form (CRF - Annexe 1), the Interview Guide (Annexe 2) and the Demographic and Health Information Form (DHIF) can be retrieved.

The final approval of the ethical committee of CHU Mont Godinne has been received on the 10<sup>th</sup> of December 2019.

#### **3.3. Study population**

The targeted population is adult patients with Crohn's disease speaking French.

Inclusion/exclusion criteria used to recruit the sample are detailed in the sections below.

#### **3.4. Identification of social media**

To choose social media that will be analysed for this research, three inclusion/exclusion criteria have been used. First, the content of social media has to be specific to Crohn's disease. So, platforms about other inflammatory bowel diseases (IBD) will be excluded. Then, to match with the population studied during patient's interview, social media have to come from the West Europe and written in French. Social media written in other languages or coming from the outside of the West Europe will be excluded. Finally, general terms and conditions of the social media will be analysed to be sure that users are aware that their online publications are public.

An initial search was performed using Google's search engine to identify Crohn's disease-specific social media forums and discussion boards, using key terms such as 'maladie de Crohn', 'forums', 'Association de patients'. Searches were conducted in May 2019. Based on these inclusion/exclusion criteria, a couple of social media have been identified:

- [www.crohnetnous.be/588-2](http://www.crohnetnous.be/588-2);
- [www.mici.be/quotidien/temoignage](http://www.mici.be/quotidien/temoignage);
- [www.carenity.com](http://www.carenity.com).
- [www.maladiedecrohn.eu](http://www.maladiedecrohn.eu);

In October 2019, social media content has been extracted from these forums. Unfortunately, one of the selected social media ([www.maladiedecrohn.eu](http://www.maladiedecrohn.eu)) has been closed before the data extraction. Social media research has only been performed on the other three social media.

Crohnetnous.be and mici.be are websites where information about symptoms, treatment and causes of the disease can be found. Also, there are testimonies of patients, but it is not possible for online users to answer or ask questions about those testimonies. In Crohnetnous.be, fifteen patients shared their experiences of the disease in several short texts and in mici.be, there are three patients who explained their everyday life.

Carecity.com is an online forum for patients with any conditions. Thanks to the search bar, three testimonies of patients diagnosed with Crohn's disease can be found. On this platform, online users can ask questions and reply to each other on the topic discussed in the testimony.

Each conversation will be extracted and collected on Word files and analysed with ATLAS.ti version 8, a software package that is designed to facilitate the storage, coding, and analysis of qualitative data.

### 3.5. Patients' face-to-face interview

#### 3.5.1. Patient eligibility and recruitment

After ethical committee approval (see section 3.2. Ethical committee), patients have been recruited through general practitioners (GP) or patients' organisation (Association francophone Crohn-RCUH (recto-colite ulcéro-hémorragique)) based on inclusion and exclusion criteria (Table 3). All participants were recruited in Belgium and were BE-French speaking.

**Table 3.** Eligibility criteria for patients' interview

INCLUSION CRITERIA	EXCLUSION CRITERIA
<ul style="list-style-type: none"> <li>• Patient is between 18 to 75 years old</li> <li>• Patient diagnosed with Crohn's disease, at least 12 months ago</li> <li>• Prior entering the study, patient is able to understand and sign voluntary the informed consent and to participate in an interview</li> </ul>	<ul style="list-style-type: none"> <li>• Patient with psychiatric condition that can impact the quality of the interview (at the discretion of the physician)</li> <li>• Patient with conditions affecting the digestive tract other than Crohn's disease (e.g., ulcerative colitis, abdominal abscesses, colonic mucosal dysplasia, intestinal obstruction, etc.)</li> <li>• Patient with an inflammatory disorder other than Crohn's disease (e.g., rheumatoid arthritis, psoriasis, etc.)</li> <li>• Patient with abdominal surgery within the last 6 months</li> </ul>

### 3.5.2. Interviews

Individual, face-to-face, approximately 60 minutes, interviews were conducted in French, using a semi-structured interview guide to facilitate the discussion. During the patients' interview, questions about these themes were asked:

- Symptoms of the disease
- Impact of the disease on the quality of life
- Treatment experience (access, burden, unmet needs, etc.)

Open-ended questions were asked to encourage the discussion with the patient and allow spontaneous answers (Bredart, Marrel, Abetz-Webb, Lasch & Acquadro, 2014).

At the beginning of the interview, the interviewer explained again the purpose of the interview, the confidentiality of the data, that the participation is voluntary and that the patient can withdraw at any time. Before the beginning of the interview, patients have been asked if they agree to be recorded. If they choose not to be recorded, interviewer would have taken notes during the interview.

### 3.6. Preparation for the analysis

Prior the analysis of the data collected through both qualitative methods, several preparations have to be done.

First, the protection of confidential patient's information is ensured. All patients' identifiable personal information (such as name, address, e-mail, city, name of the doctor, ...) were removed from all the documents used for the analysis. After the confirmation of all the eligibility criteria, each patient was anonymised. For the interviews, an identification code was created for each patient that consists in a 4-digit subject identification number: the first two numbers represent the GP or the patient organisation and the last two are specific to the patient.

For social media research, permission of the websites was checked to ensure the content we are interested in can be accessed and collected. No post content has been reproduced in this work; all quotes, when used, have been paraphrased to ensure they are not discoverable through a Google search.

Also, to protect the identity of the participant of the interview and the social users, the personal pronoun "he" was used for all the patients throughout this study. There is an exception when pregnancy or periods are discussed.

Second, each transcript has been carefully classified. All the audio files have been transcript and enter in ATLAS.ti to be analysed. Regarding social media research, texts collected on each platform have also been entered in ATLAS.ti.

Third, a coding book was created for the analysis. The coding book resumes all the codes that were used during the analysis. For each code used, a short definition of the code is provided to ensure that the code is used in a reliable way throughout the analysis. The coding book and definition of all the codes can be found in the Annexe 3.

Prior the analysis, codes were created based on the literature and the research questions. Nevertheless, if new relevant information is found in a transcript, new code can be created and

added in the coding book. Because new codes are created, transcripts have to be analysed several times. This analysis is an iterative process.

### 3.7. Analysis

Interview transcription and content from the blogs and forums have been analysed using the ATLAS.ti software. This software is designed to analyse qualitative data. Using software allows sorting the information. Indeed, a huge amount of information can be found in patients' face-to-face interview and social media research. So, it is important to rigorously classify all this information.

Each transcript and forums/blogs content have been coded with ATLAS.ti using a thematic approach thanks to the coding book. The concepts coded concerned disease symptoms, impacts, and treatments. In addition, another class of codes (i.e., the descriptors) was developed to describe each concept coded. This provides new classifications in the first classification. Examples of descriptors are severity, frequency, more bothersome, etc. So, some information can have more than one code. An example of social media analysis and a representation of codes can be found in the Figures 2 and 3.

#### Réflexions déplacées

Mes amis ont toujours fait preuve de compréhension pour ma situation. Cependant, certaines remarques déplacées fusent parfois, le plus souvent avec les meilleures intentions. Je suis de corpulence assez forte et lorsque j'avais des crises je maigrissais beaucoup. Je recevais alors de nombreux compliments à ce sujet mais je me sentais très mal. Les gens ne comprennent pas qu'on ne puisse pas déceler de signes extérieurs de la maladie et que, si je maigris, c'est parce que je mange à peine et que je souffre de diarrhées permanentes. On a du mal à trouver ce genre de remarques positives et pour ma part je les trouvais très frustrantes.]

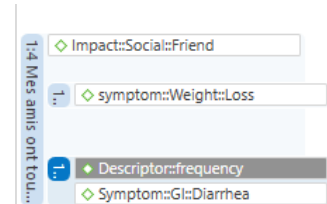


Figure 2: Example of social media analysis and representation of codes in ATLAS.ti version 8

Figure 3: Example of transcript in ATLAS.ti

Finally, when the base size and the run length is determined, the new information threshold had to be chosen. The new information threshold is the proportion of new information collected during the interviews. At a given point of the qualitative research, evidence that saturation is reached could be assessed at two levels of new information collected:  $\leq 5\%$  new information and no new information (represented by 0%).

Then such as for social media, the query tool of ATLAS.ti has been used to analyse all the transcripts together.

Finally, an analysis has been performed to compare the content of information collected through the two qualitative methods. Several types of information were compared based on the study objectives:

- Primary objective: The number of concepts (symptoms, impacts of the disease and treatment experience and expectations) and level of detail of each concept (duration, frequency, and severity has been analysed).
- Secondary objective: the language (e.g., words, expressions) used by the patients to describe their experience with the disease and treatment. Textual cues have been taking into account in the analysis of social media content.

Health and demographic patients' information of the patients interviewed were collected and described in a descriptive way. This information is not available for social media.

Finally, sample size of the two populations was compared. As said before, anonymous texts or pseudonyms are frequent on the Internet and fake profiles can be hidden behind them. Nevertheless, to compare the sample size of both methods, two assumptions were made: every user is diagnosed with Crohn's disease and one patient did not register using two different profile names.

## 4. Analysis

After the analysis of both methods, it appeared that social media research and face-to-face patients' interview allow highlighting a different number of concepts. Social media had reported a total of 29 concepts, including 14 symptoms, 4 signs, 6 impacts, 5 treatment-related concepts. And patients interviewed had reported a total of 35 concepts, including 20 symptoms, 6 signs, 8 impacts, 6 treatment-related concepts.

### 4.1. Social media

#### 4.1.1. Study population

Three social media have been analysed in this research. The sample included twenty-seven users. Exact population characteristics are not known, but based on the users' name, it has been assumed that there were six men and seventeen women; the last four users used a pseudonym and their gender could not be assessed. Participants' age is known only for one of the three platforms, crohnetnous.be. However, testimonies are not dated. So, the current age of the participant is not known.

#### 4.1.2. Symptoms/Signs of Crohn's disease

##### 4.1.2.1 Gastrointestinal symptoms

Gastrointestinal (GI) symptoms were the most frequently reported symptoms by social media users. Among GI symptoms, abdominal pain (n=17; 62%), diarrhoea (n=17; 62%), bowel movement urgency (n=6; 22%), daily or night stool frequency (n=4; 15%), nausea (n=5; 18%), vomiting (n=3; 11%), blood in the stools (n=1; 4%) and flatulence (n=1; 4%) were described (Figure 4).

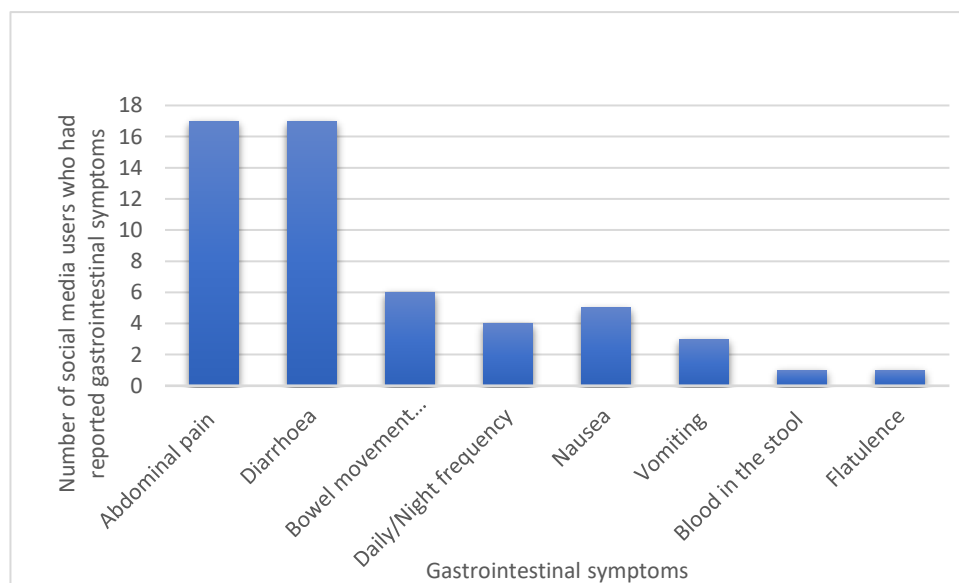


Figure 4: Frequency of gastrointestinal symptoms reported by social media users

Abdominal pain (n=17; 62%) and diarrhoea (n=17; 62%) were the most frequently reported symptom by social media users. Intensity and duration of the abdominal pain vary from patient to patient. Some users describe the abdominal pain like cramps (acute pain, short duration), for other patients, abdominal pain is endured several weeks in a row. Sometimes, pain is so unbearable that patients have to stop their activities. One of them explained that when he suffers from abdominal pain, he has to lay in bed in particular position to try to reduce it. Such pain can cause nausea to the patient. However, few patients are suffering from a benign form and have less abdominal pain. A patient reported that he has only one “attack” per year, during approximately two weeks.

Abdominal pain can be linked to other factors such as the stress, the period for women, abscesses or occlusion. Indeed, patients reported that the intensity of their cramps are increased when they are stressed, caused by their job, medical visit, etc.

Regarding the diarrhoea, its frequency and duration vary from patient to patient: some patients have daily diarrhoea, during months or weeks, while other patients have only one or two episodes of diarrhoea per year. Adequate treatment can decrease, the frequency of diarrhoea. Severity of the diarrhoea can be severe. A user reported that each time, he had to go immediately to the hospital to regulate his electrolytes. For these patients, diarrhoea could be a consequence of several factors. Two have been reported by the social media users: the stress and a surgical resection of the intestine. In the last case, diarrhoea is chronic.

Bowel movement urgency (n=6; 22%) has also been reported by the social media users. For instead, the fact that they often have to go urgently in the toilet and have frequently “small accidents”. Sometimes, when they are suffering from cramps, they know that they have to go to the toilet immediately. Two users have reported that they asked a card to disable people because they feel the emergency regularly to go to the toilet.

Daily or night stool frequency (n=4; 15%) was reported by four social media users. They explained that they have to go more frequently to the toilets than before the apparition of their disease. Three examples were explained by the users: going twelve times a day to the toilet or eight times during some nights, or they could not take the count of it because it was too high. Nevertheless, their daily frequency decrease with the adequate treatment.

Nausea was reported by five users (n=5; 18%). For some users, nausea can be a part of their daily life. For others, nausea was the consequences of repetitive overwhelming abdominal pain. As for the previous symptoms, patients suffered from nausea for weeks and weeks. From time to time, nausea can be associated with vomiting (n=3; 11%).

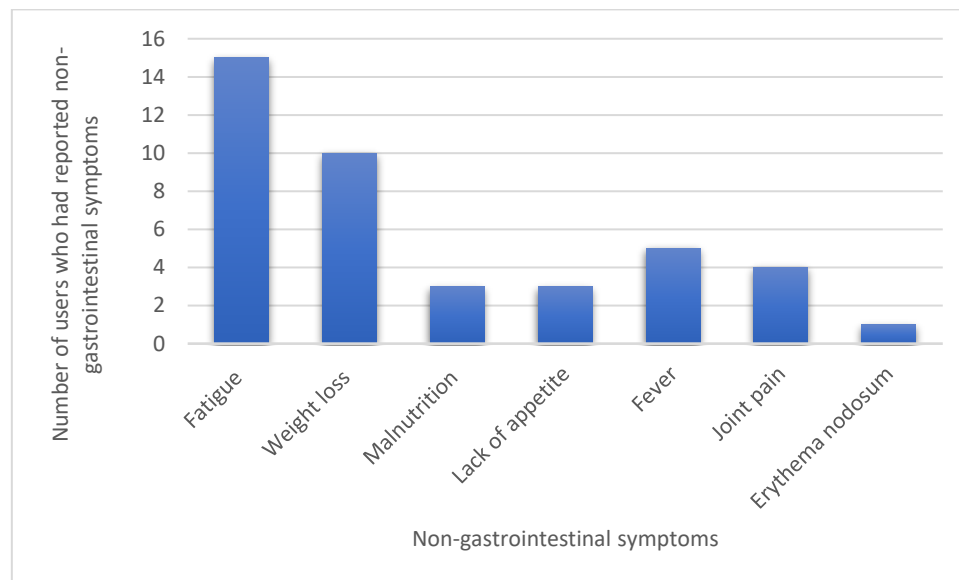
Finally, few other GI symptoms were reported but not well explained by social media users: flatulence (n=1; 4%) and blood in the stools (n=1; 4%).

#### 4.1.2.2. Other symptoms

In addition to the GI symptoms, other symptoms have been reported by the social media users (Figure 5).

The most burdensome symptom was fatigue (n=15; 56%). Frequency of fatigue can vary among social media users: five users explained that they are suffering from fatigue every day: most of the time they are completely exhausted, even if they are taking their medication. They

have to listen to their body, to understand what they are able to do. For example, a user explained that he did not work full-time anymore because he needs to sleep two to three hours each afternoon, to rest. Another said that he always feels as he went on an exhausting outing, but without going outside. And only one patient is exhausted during periods of stress.



**Figure 5: Frequency of non-gastrointestinal symptoms reported by social media users**

Also, for the younger patients, fatigue is a burden because they are not able to do what the other young people do: they are not able to go out all night, follow the regular courses for their studies or show what they are able to do for their first job.

To cope with fatigue, social media users explained that they have to rest: if they are not working for a few weeks, they are full of energy again. Also, two users have reported that they asked a card to disable people. Sometimes they feel too weak and too tired to continue driving. This is a relief for them to know that they can find a parking spot easily, to rest.

Then, weight loss ( $n=10$ ; 37%) has been widely reported in the social media research. With Crohn's disease, the weight loss can be impressive for patients and their environment. Here are few examples reported: in few months a patient lost 18 kilograms passing from 53 kilograms to 35 kilograms, in a year a user lost more than 15 kilograms, in a week another patient lost approximately 6 kilograms, or another lost 20 kilograms after two surgery and few months spent in the hospital.

Patients or their environment are frightened about their sudden weight loss and their consequence. Indeed, because of this slimming, some patients had to be admitted to the hospital to boost their energy. And some of them have to be careful to eat sufficiently to avoid being underweight. Nevertheless, one patient has signalled that he is satisfied by his weight loss. He had a lot of compliments from his environment.

Then, patients reported difficulties to absorb the nutrients ( $n=3$ ; 11%) and a lack of appetite ( $n=3$ ; 11%). They have to watch certain factors because of their malnutrition: their hydration,



the level of their vitamins, etc. A social media user reported that every fifteen days, he had to go to the hospital to have a vitamins' perfusion to compensate his deficiencies.

Lastly, few other symptoms have been reported but not well explained by social media users such as fever (n=5; 18%), joint pain (n=4; 15%) and erythema nodosum (n=1; 4%). Fever can be high for patients with Crohn's disease. Indeed, for one of them, his fever increased until 40 degree Celsius. Sometimes, fever lasts for weeks. For the joint pain, it was reported by one user that when he practised judo, he injured a lot because of his articulations were already weak. Finally, only one patient reported erythema nodosum and did not give any more information about it.

#### 4.1.2.3. Signs

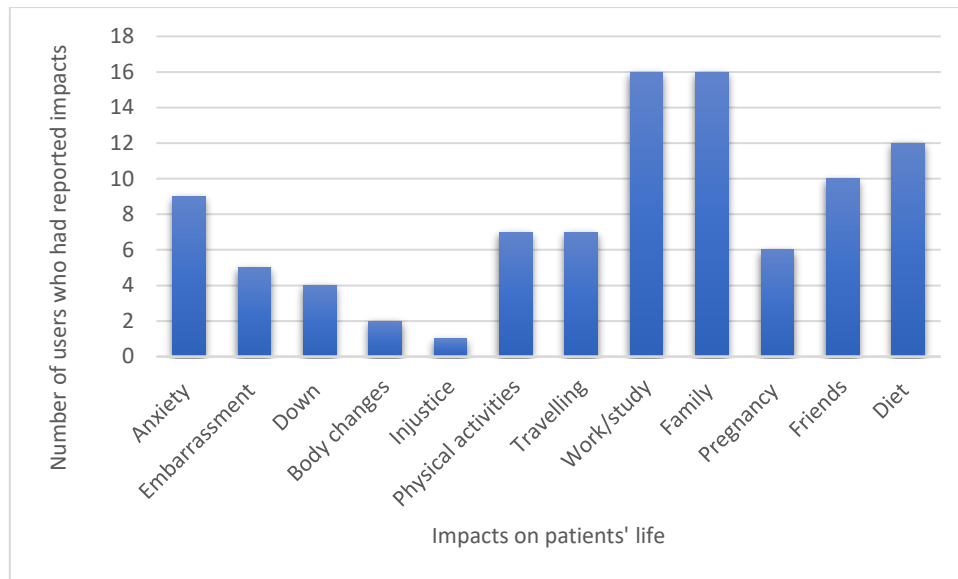
Besides GI symptoms, social media users have also reported GI signs of the disease. Those signs are bowel inflammation (n=7; 26%), abscesses (n=5; 18%), occlusions (n=3; 11%) and intestine lesions (n=2; 7%) in the colon or in the anus. Bowels' inflammations are generally associated with abdominal pain. One patient reported that he was thinking that it was an appendicitis because of the intensity of the pain, but after scanners it appears that it was an intestine's inflammation. Also, for other patients, blood samples had shown that markers of inflammation were high.

Also, anal and internal abscesses were reported by five social media users. Generally, it causes severe pain to the patient. Users explained that they had to undergo surgery to treat their abscesses. Severity of the abscess can vary from one user to another. One shared that two litters of pus were drained during his surgery.

Then, three social media users have reported occlusions. As for the abscess, occlusions are really painful for the patient: it was described as an infernal and stabbing pain, when the food bowl goes down through the intestine and push against the occlusion. Even with treatment, some patients did not feel any relief. They had to wait until the pain progressively disappears. For other patients, surgery and treatment are a real relief. The occlusions are less frequent or could disappear within a day. Also, a user reported that surgeon had placed a temporary stoma until he did have any more occlusion and until the inflammation was treated. The Collins English Dictionary defined the stoma as "an artificial opening made in a tubular organ, especially the colon or ileum" (Collins, 2020). This opening can be connected to the outside and a pocket to collect body fluids or waste products.

#### 4.1.2. Impacts of Crohn's disease

Impacts of Crohn's disease have been classified in six categories: emotional impacts, physical impacts, travel, work or school, social impacts and impacts about patients' nutrition. The frequency of these impacts is represented in the Figure 6.



**Figure 6: Frequency of impacts reported by social media users**

#### 4.1.2.1. Emotional impacts

The most frequently reported emotional impact was anxiety (n=9; 33%). Nine social media users felt anxious because of the perception from other people, and/or about their disease, treatment, or future. Patients described a lack of empathy and understanding of their condition by their environment. A user said that he had taken antidepressants only to cope with the perception others have about his condition.

Because the symptoms of the disease are evolving, patients live with periods of remissions and relapses. During the relapse, they endure many things, as well physically as mentally. Some of them are frightened about living again those relapses. Also, some users share their anxiety about finding toilet quickly enough when it is needed. A user described he calculated the time he had between two bowel movements to know how long he had to do his shopping. For him, even the most common activity could be a source of stress. To avoid this stress, two users have asked a card to disable people, to be sure that they have a parking spot in case of emergency.

Anxiety can also be linked to resection surgery. A user was so stressed that he was unable to do anything before his surgery. He explained that he was waiting days passed until the surgery like “a prisoner in the death row”.

Finally, youngest patients described anxiety about their future (work, relationship, family, having children): will it be possible to combine professional life and their condition? What will be the impact on their relationships? Will it be possible to meet someone who accepts the disease? Will they be able to have children with their condition? Will they have enough energy to take care of their children?

Then, embarrassment has been reported by five social media users (n=5; 18%). Because of the embarrassment caused by their condition, a user totally rejected it. Also, patients who are honest about it to their environment, can be afraid of bothering people about it.

In addition, four users described feeling deeply down (n=4; 15%). Because of the difficulties that they are facing, patients may feel depressed. Crohn’s disease can encourage irritability and

bad moods, for one user. Also, accepting that their bodies change was emotionally difficult for them (n=2; 7%). For example, a patient explained that he was convinced that he will stay alone forever because he had a stoma. For him, it had taken a long time to accept his “new body” with a stoma.

Finally, a social media user reported a huge sense of injustice (n=1; 4%) against his condition. He described feeling really bad because he knew that he suffered from a chronic condition.

#### 4.1.2.2. Physical impacts

Physical impacts (n=7; 26%) reported varied a lot among the seven users who have written about it. Some got all their energy from their physical activity, the other felt the fatigue when they practised their sport.

Four social media users explained the importance of physical activities in their life. It is important for their health, both mental and physical. For them, being sick is not an obstacle to practise a physical activity. Rather, sport increased well-being and might help to face the stress. Patients explained that they felt better, more relaxed after their activities. Also, sport could give them energy. A patient explained that if he does not practise sport for days, he feels more the fatigue.

Three types of physical impacts had been shared by social media users. First, despite their disease, patients can continue their physical activities as usual. Secondly, users had to adapt their physical activities to their condition. For instance, a user had to find a sport without contact, such as hockey, because of his joint pain. Another example is that a patient had to stop his activities temporarily because he had to undergo surgery. Finally, only two users reported that since their diagnosis, they are not able anymore to practise it regularly. One explained that walking could be extremely exhaustive for him, even if he was athletic before his diagnosis.

#### 4.1.2.3. Travel

Even when they are travelling, Crohn's disease takes a huge place in their lives. An extra organisation is needed for those patients (n=7; 26%). When they catch a plane, they have to take their precautions. For instance, some of them take extra pants, sanitary napkins, their own food, the right quantity of their treatment, etc. One has reported that he carefully chooses his seat in the aeroplane: next to the toilet.

Also, certain destinations are not recommended for them. Because they are more sensitive to bacteria, a small food poisoning can cause diarrhoea for weeks. So, they have to travel to countries where the quality of food is not sure and where the healthcare system is not well developed. More, some tropical countries are forbidden for these patients. To obtain their visa for these countries, people have to be vaccinated against yellow fever, for example. Because the immune system of those patients is weaker, they cannot be vaccinated. Finally, they have to choose places where they can easily rest. They have to avoid too intense activities.

#### 4.1.2.4. Work/school

Sixteen social media users (n=16; 59%) had written about the impact of the disease on their work or studies. In most cases, social media users had reported that they had to adapt their jobs to their condition. Four of them had to quit their job and stop working because of the severity of their condition (n=4; 15%). Nine patients had to change their work for another job or had to work in part-time (n=9; 3%). Users had to change job to reduce stress or to find a job that is less physical for them. Indeed, a user explained that the stress linked to his work was so intense that it made his disease more severe. Because of it, he decided to stop his activity and change his job, in a less stressful area. Also, a user was working for a store and had to change his job because he had to walk a lot, and at the end of the day he was too tired.

Then, it has been reported that the users had to take frequently medical leave, for a few days, weeks or months. Their absences are justified because they had to undergo surgery, they have to burdensome side effect from their treatment, they had severe attacks, etc. They explained how complicated it could be to try to keep their job when they are often sick.

More, working relationship with their colleagues are impacted by the disease. First, all the social media users are not always transparent with their manager and their colleagues about their disease. Because for the work application, manager can be frightened about their condition. Also, even if their co-workers are aware of their condition, users had to face the jalousie or prejudices from their colleagues. They were not comprehensive and thought that he was lazy and that he does not want to work. Hopefully, this was not the case for all the users: some had really good work experiences with their colleagues. Indeed, colleagues of a social media users shown understanding about their condition. Sometimes, they had discussed with managers and colleagues to find how patients could perform his job in the best possible conditions.

Finally, for the younger patients, gastrointestinal symptoms, fatigue, or joint pain had an impact on the studies of other users. Their Crohn's disease had an impact on their school attendance: because of their symptoms there is frequently absents from school. Sometimes their study programs had to be adapted and spread on few years. One user had to give up his studies because he could not attend classes, or symptoms were accentuated by the stress of the study and examens.

Also, one patient explained that the choice of his study was not easy. He decided to become a nurse. He knew that this work is not recommended for him because it is really tiring. However, his disease had no influence on his studies, except for some absence because of clinical examination he had to do.

#### 4.1.2.5. Social impacts

Sixteen social media users (n=16; 59%) had written online about the support of their family. Everyone explained how much their family were supportive: even if they could be worried about their disease, their family support them in the good and bad days. Most of the time, the partner is a real pillar for the patient.

However, love relationships are impacted by Crohn's disease. Often patients' disease was already diagnosed when they met their companion. Quickly they have to explain to them their conditions and their impact on their lives. This is hit-or-miss for those patients. In this

discussion, users explained that they felt vulnerable. They did not know how their date will react. Will they know the disease? Will they be comprehensive or not? Will they accept to be engaged with a person suffering from Crohn's disease?

Moreover, another consideration reported by social media users about having children (n=6; 22%). First, before being pregnant, patients had to be in remission. For ten years, one user was sick, and she could not have a child in this condition. Also, patients are afraid to be too weak and exhaustive to raise children. Then, the inheritance of the Crohn's disease is not well known. Patients think a lot before deciding to have children. Finally, pregnancy for patients suffering from Crohn's disease can be physically difficult. After three months of pregnancy, even if she was in remission, the symptoms of one social media user had reappeared: diarrhoea, fatigue and joint pain. She had to take cortisone again and her recovery was as well hard.

To finish with the social impact, the relationship with their friends has been analysed (n=10; 37%). Generally, users were frightened about the reaction. Nevertheless, friends frequently reacted with empathy and comprehension, even if this disease has a serious impact on their social life. Because of their symptoms or of convalescence, users explained that they had to be cancelled or come back home earlier. A twenty-year-old patient had written on social media that he could not do big parties since his diagnosis. The social pressure encouraged him to drink alcohol and it made him sick. Finally, there are often people who did not well accept their disease. Because patients did not look sick, their environment could say remarks that could be perceived badly by the patient.

#### 4.1.2.6. Diet

The last category of the impact on the patients' lives is the diet (n=12; 44%). Finding the right dietary plan is a very empiric approach for these patients. Indeed, users have reported that they did have only few information about their nutrition from their gastroenterologist. Avoiding alcohol and cigarettes is the most reported advice. Two users had consulted a dietitian to be guided. Also, it is possible that patient support some food and suddenly they did not tolerate it anymore. Even with times, patients had to find the right balance in their diet to avoid being sick.

Social media users explained that they make a list with food they cannot eat. This list is quite different from patient to patient. However, few ingredients are common on their list: raw vegetables in particular crudeness, fruits, fibres, or alcohol have to be avoided. Generally, they also try to eliminate fatty foods from their diet. Wrong diet can induce occlusions for those patients. One had experienced it after eating asparagus.

Because of particular diet they have to follow, going to the restaurant to a party is a challenge. They have to pay attention to what they could eat and drink. A user had reported that he went to the restaurant only when he had nothing to do the next morning.

Nevertheless, three users had signalled that they did not have to change their diet. The condition of some users is quite moderate. This means that their symptoms are less severe and frequent. Generally, they can eat and drink what they want. They don't deny themselves anything good. One explained that with the adequate treatment and with a healthy life, his condition has no impact on his life: he can eat and drink everything he wants.

#### 4.1.3. Treatments of Crohn's disease

Finding the right treatment could be a long journey for the patient. Often patients had to try several medications before finding the one that is efficient for them. Patients had to change their medications for three main reasons: either the treatment is not working on them, either symptoms gradually came back after a few years, or because of the side effects of their treatment.

Regarding side effect (n=11; 41%), some have been reported on social media, but without explaining which medication they were taken. Some had lost their hair, others had allergies, or even rheumatoid arthritis. Also, a patient had undergone two cataract surgery in a year.

Hopefully, most of social media users signalled that they finally found the right medication for them. Indeed, their GI symptoms and number of attacks decreased. A social media user explained that he reacted perfectly to his treatment. Thanks to it, nothing remains him that he had Crohn's disease.

Then, a user had reported that when he felt better, he tends to take less regularly his medication (n=1; 4%). But this leads to more severe crises and he had to be hospitalised again. Since he takes his medication scrupulously.

Also, operation (n=10; 37%) and hospitalisation (n=11; 41%) have been reported on social media. Operations can help to treat occlusion, abscesses, or to reduce symptoms via resection surgery. Thanks to the operations, associated with the right treatment, symptoms of the disease can decrease.

Hospitalisation could last for a short or long time according to the causes of it. Patients were hospitalised because they need to rest and to recover. Some were taken to the hospital after fainting, diarrhoea, attacks, or because he had lost almost twenty kilograms. A user was so weak that he had to be fed through a tube for two weeks.

#### 4.2. Patient interviews

##### 4.2.1. Study population

Ten patients took part in the interviews: two men and eight women aged from 22 to 63 years old. Mean age was 36 years old. The number of years since diagnosis ranged from 2 years until 40 years ago. Mean number of years since diagnosis was 14 years ago. Seven of the participants are workers and the three others are still a student. No one was in medical leave.

The disease severity, as reported by the GP, included seven patients with a moderate disease, three with a severe disease. However, no patient with a very severe Crohn's disease was interviewed. For example, no participant treated with a stoma was in the patient's face-to-face interview sample.

Regarding comorbidities, three participants suffered from one other disease: lung cancer, heart palpitations and bipolar disorder.

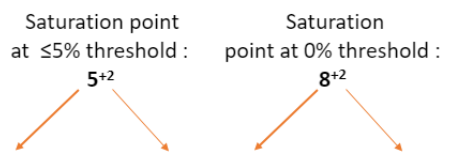
Out of the ten patients interviewed, seven were in remission at the moment of the interview and currently experienced no symptom. During the interview, these participants described symptoms and impacts they experienced since the diagnosis, when they were not in remission.

#### 4.2.2. Saturation

Generally, as explained in the introduction, in qualitative interviews, the concept of saturation is used to determine sample size and we do not know upfront how many interviews will be needed. For the saturation, several parameters had to be chosen prior the calculation. Here, the base size is four interviews and a set of two interviews represents the run length. The saturation for the face-to-face patients' interview is calculated in the table 5 below.

At the seventh interview, the new information collected during the last run is below the  $\leq 5\%$  threshold. This means that the number of new information is decreasing. Because in the last two interviews, only a few numbers of new concepts had been collected, it could be said that saturation is reached at the fifth interview. This is annotated  $5^{+2}$ , to indicate that in total seven interviews had been conducted and that the saturation was reached at the fifth.

**Table 5: Calculation of the saturation**



Saturation point at  $\leq 5\%$  threshold :  $5^{+2}$

Saturation point at  $0\%$  threshold :  $8^{+2}$

Interview number	1	2	3	4	5	6	7	8	9	10
New concepts per interviews	19	9	10	4	5	0	1	4	0	0
New concepts in run				42		5	1	5	4	0
Percentage change over base						12%	2%	12%	9%	0%

Base size: 4 interviews (interviews 1-4)

Run length: 2 interviews (interviews 5-6, 7-8, 9-10)

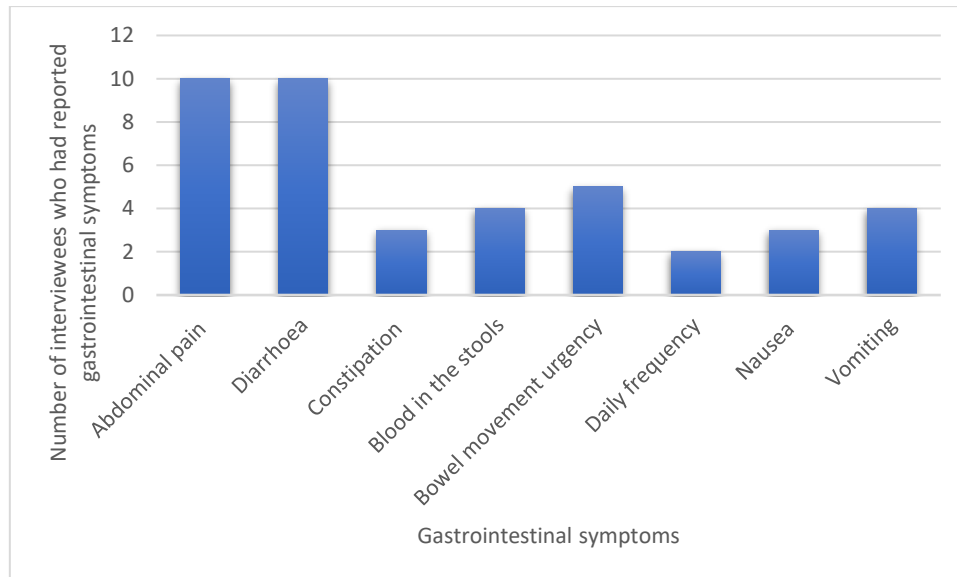
However, the level of saturation reached is at the  $\leq 5\%$  threshold. To be more confident in the result, a level of saturation of  $0\%$  threshold had to be reached. So, the interviews have to be continued. At the tenth interview, the  $0\%$  new information was reached at the  $8^{+2}$  interviews. This means that ten interviews had been performed and the saturation was reached at the eighth interview.

After calculating the saturation, one question could be asked. First, how can we be sure that no important information is missing, if the interviews are stopped at this point? Indeed, if more interviews are conducted, maybe new relevant information can be highlighted by the patient. More, in this study, it appears that the last two patients interviewed have a moderate Crohn's disease. So, they have less severe symptoms and also less impacts on their life. To truly answer this question, no one knows if the next interview will bring new relevant concepts to this research unless if more interviews will be conducted. But Guest and al. (2020) explained that this is where researchers had to rely on empirical research. Indeed, empirical research had proved that the emergence of new relevant information is reducing over time.

### 4.2.3. Symptoms/Signs of Crohn's disease

#### 4.2.3.1. Gastrointestinal symptoms

Gastrointestinal symptoms have been the most reported symptoms. Among GI symptoms, abdominal pain (n=10; 100%), diarrhoea (n=10; 100%), blood in the stools (n=4; 40%), nausea (n=3; 30%) and vomiting (n=4; 40%), bowel movement urgency (n=5; 50%), constipation (n=3; 30%) and belly bloating (n=1; 10%) are included (Figure 7).



**Figure 7: Frequency of gastrointestinal symptoms reported during the face-to-face patients' interview**

All the patients (n=10; 100%) reported abdominal pain and this symptom is the most bothersome symptom for 3 patients.

Abdominal pain experience varies among patients. One patient described the impression of having needles in his bowels. Two patients compared the pain with periods or birth delivery contractions. One patient described that the pain is so severe that no one can touch her belly, even her doctor. Another patient shared that: *“Le pire c’est les crampes en fait, c’est vraiment les crampes assez fortes qui parfois me réveillent la nuit avec des sueurs froides.”* (01-01; F 30yo). Abdominal pain is sometimes experienced together with other symptoms, like spasms in the intestine and stomach bloating.

Location of the pain is generally related to the regions where the inflammation is more severe. Sometimes, in these inflamed areas, ulcers can be found. Severity of the symptoms is dependent on the inflammation severity and the presence of ulcers. Patients explained that with an efficient treatment and a proper monitoring of their disease, the inflammation and ulcers disappeared slowly.

Frequency of abdominal pain varies. Some patients felt it continuously at the beginning of their disease, but the pain significantly decreased with an efficient treatment. Other patients described the pain is still continuously present even three or four years after their diagnosis. Abdominal pain severity seems increased by some factors like stress.

Diarrhoea was reported by all the patients (n=10; 100%) and is the most bothersome symptom for 3 patients. One had reported: *“J’avais des diarrhées très fortes, je me vidais littéralement.”*



(04-01; F 31yo) And that the diarrhoea often comes with a strong smell. Frequency of the diarrhoea can be high: one patient reported that at the beginning of his disease, he had to go to the toilets a dozen times per day.

Three patients explained that after long periods of diarrhoea they experienced long periods of constipation (n=3; 30%). One patient experienced three to four months of diarrhoea followed by three to four months of constipation.

Patients described the emotional impact (shame, embarrassment) of diarrhoea and the impact on their daily life because they have to find toilets all the time (a patient explained that he becomes a “radar to find toilets”) and adjust their diet.

Four patients reported blood in their stools (n=4; 40%). Sometimes, the presence of blood was explained by the presence of haemorrhoids. Haemorrhoids (n=2; 20%) was the most bothersome sign of the disease for one participant because his haemorrhoids became a marisca because it was not well treated.

Five patients reported the feeling of bowel movement urgency (n=5; 50%). Sometimes, they have the impression that they have urgent needs but in reality, they do not have to go to the bathroom. However, these urgent needs, real or not, could happen anywhere. For this reason, a patient shared that he asked a specific medical card that explained his disease and gives a rapid access to toilets. He called it his “poop card”. Nevertheless, he tries to use it as little as possible, because he is ashamed of it.

Daily frequency was reported by two patients interviewed (n=2; 20%). Two examples were given by them: going up to a dozen times per day to the toilets or spending the whole morning in the bathroom because of their symptoms.

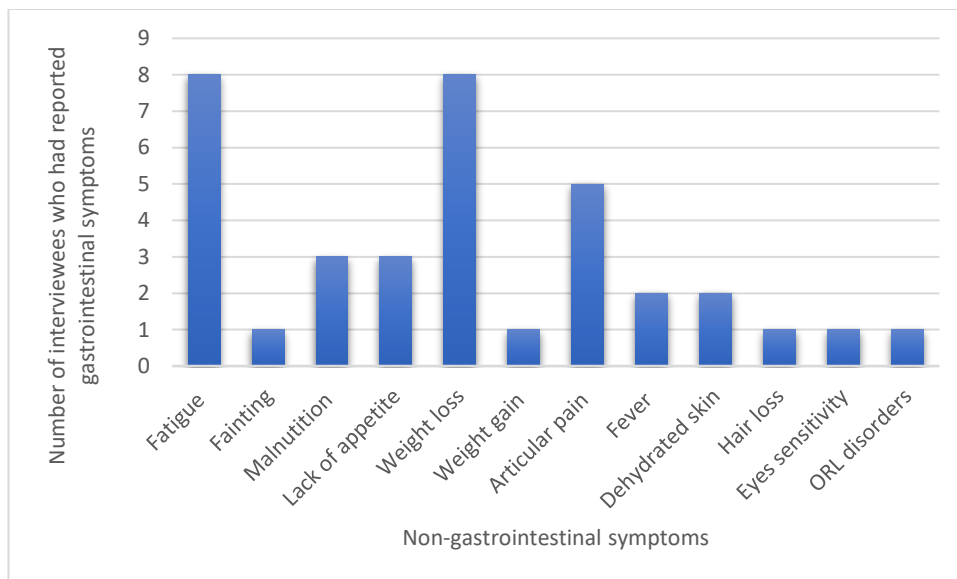
Vomiting (n=4) and nausea (n=3) were reported during interviews. One patient experienced frequent nausea and, less frequently, vomiting. Another only had nausea and vomiting two or three times a year. Generally, this happens when he has an attack: he felt intense abdominal pain and had strong diarrhoea. Those attacks could last for several days. One patient (diagnosed when he was adolescent) described that: “*il y avait des personnes qui croyaient que j’étais boulimique. Et que je me faisais vomir, alors que pas du tout en fait.*” (04-04; F 40 yo). For her, this was the most bothersome symptom of Crohn’s disease.

#### 4.2.3.2. Other symptoms

Non-gastrointestinal symptoms reported by patients during the interviewed are illustrated in the Figure 8. Fatigue was the most frequently reported symptoms (n=8; 80%) and also the most burdensome one for three patients.

Six of them explained that fatigue is a part of their daily life and that they have difficulties to recover. For example, here is the experience of a participant: “*La fatigue chronique est un très gros problème. Parce que je peux dormir 12h par nuit et me réveiller aussi fatiguée que la veille. And patients described physical and mental fatigue.*” (02-02; F 23yo) A patient explained that he could suffer from a low moral because of his fatigue. However, for few other patients, they only experienced fatigue after an attack. Here, they shared that they could do nothing and they need time to recover. But some participant shared their incertitude about the cause of the fatigue. Four interviewees thought that fatigue could also be a consequence of their

treatment, the malnutrition, their lack of appetite or their weight loss. In addition, a patient had also experienced few times fainting because he was too exhausted.



**Figure 8: Frequency of non-gastrointestinal symptoms reported during the face-to-face patients' interview**

Three patients experienced a lack of appetite. For one of them, it was more than a lack of appetite: his body refused to eat. According to her: *“C'était vraiment physique. Quand je mangeais... je mangeais deux bouchées et puis j'avais ma gorge qui me lançait et qui m'étranglait. Je voulais manger, mais c'est mon corps qui refusait de manger.”* (02-02; F 23yo) At this time, this patient suffered from nutrition deficiency. Two others also had bad results in their blood samples such as a deficiency in vitamin B12, because they had to change their diet to limit their symptoms.

Due to their disease, eight patients had lost a lot of weight (n=8; 80%). Here are few examples: a loss of twenty-five kilograms in a year, fifteen kilograms in two months, a dozen kilograms in a month, five or six kilograms in a month, two kilograms and half in a week, etc. However, one patient had reported a weight gain (n=1; 10%) rather than a weight loss. In few months, he had gained 12 kilograms.

Another non-gastrointestinal symptom widely reported by the participants (n= 5; 50%) is the joint pain, located in ankles, knees, hips, hands, wrists or back. Patients had compared themselves to the elderly: *“Quand je me lève, je me lève comme une petite vieille. Pendant la nuit, en fait j'ai les articulations des chevilles qui se bloquent. Donc quand je me lève le matin je marche comme une vieille. Je dis toujours comme une vieille, mais il y a sûrement des vieilles plus dynamiques que moi. Et je marche tout doucement, avec des tout petits pas, le temps que la cheville se réchauffe.”* (04-04; F 40yo) For instead, in the morning when their ankles are rigid, they had to walk slowly, making little steps. Joint pain could be continuous or infrequent.

Moreover, some symptoms appeared at the beginning of their disease were barely reported: two patients had signalled around 40 of fever (n=2; 20%), two others had dehydrated skins

(n=2; 20%), one had loose his hair (n=1; 10%) and, finally the eyes of a participant are extremely sensitive to the light (n=1; 10%).

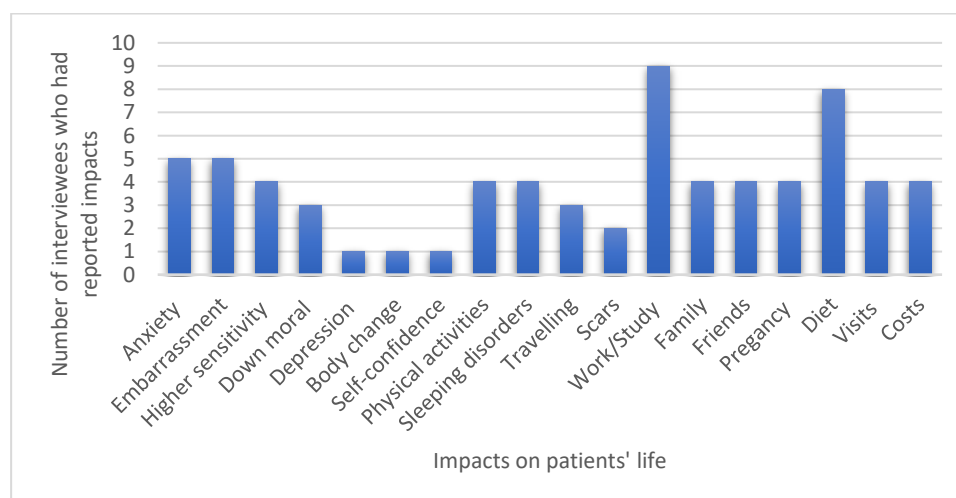
Finally, a patient had shared that his Crohn's disease attacked all his digestive tube, from the stomach to the anus (n=1; 10%). Because of his disease, he had a lot of gastric reflux. Because of the gastric reflux, his teeth are demineralised and his sinuses are burned, causing constant sinusitis.

#### 4.2.3.3. Signs

Besides GI symptoms, social media users have barely reported GI signs of the disease. Those signs are bowel inflammation (n=3; 30%), occlusions (n=2; 20%), haemorrhoids (n=2; 20%), abscess (n=2; 20%), fistula (n=2, 20%) and diverticula (n=1, 10%). Regarding patients who had reported occlusions, they had to be operated to treat them.

#### 4.2.4. Impacts of Crohn's disease

Impacts of Crohn's disease (Figure 9) have been classified in eight categories: emotional impacts, physical impacts, travel, sleeping disorders, work or school, social impacts, impacts about patients' nutrition and frequency of their visits in the hospital.



**Figure 9: Impacts reported by participants during the face-to-face interview**

##### 4.2.4.1 Emotional impacts

Anxiety (n=5; 50%), embarrassment (n=5; 50%) and a higher sensitivity (n=4; 40%) are the most reported emotional symptoms. Patients are anxious about the symptoms of their disease, the medical examination and their treatment. For example, two patients did not dare going outside for a long time because they are frightened of feeling bowel movement urgency. Four participants were anxious during visits to the hospital because they know that the medical examination can be painful. Lastly, a patient reported that he already changed few times his treatment. Now, he is afraid of having no more possibility of treatment when his current treatment will be less efficient.

Five patients are really embarrassed and ashamed of their disease. They are ashamed of their feeling of bowel movement urgency that could happen at any time, about the smell of it, etc. Also, it happened that patients could not hold back: it happened that they could not arrive on time to the toilet. One patient had reported that he had few “accidents” during medical examination, especially during colonoscopies.

Then, patients explained that they are more sensitive and emotional than before the diagnosis. An interviewee signalled that: “*Avec le diagnostic, au début, on pleure toutes les larmes de son corps.*” (04-02; F 46yo)

Also, patients (n=3; 30%) noticed that Crohn’s disease can have a huge impact on their moral: they experienced periods when their morale is down. A participant explained that most of the time, he felt well. But he is often closed to himself. During these moments, he could not do anything and cry alone. Moreover, one participant is also taking antidepressants and anxiolytics, since the beginning of his disease. He said that he needs these medications to support his disease.

Another patient shared that he had difficulties to accept his body since he is sick (n=1; 10%). Indeed, he had gained twelve kilograms. He did not feel attractive and desirable not only for himself but also for his partner.

Lastly, one patient interviewed had signalled that his self-confidence (n=1; 10%) had considerably decreased. After a year suffering from an unstable Crohn’s disease, he began to question his abilities and he doubted that he deserved to have such a supportive family and friends. However, he learned to better manages his self-confidence and currently he only had doubts during difficult times, such as school exams.

#### 4.2.4.2. Physical impacts

Physical impacts of the Crohn’s disease could vary among patients. Six (60%) continued to practise regularly sports, but the four others (40%) had to stop it.

For the six patients who are still able to practise physical activities, getting fit is really important to face their chronic fatigue. However, at the end of their physical activities, they felt more exhausted.

The four other participants explained that they had to stop or to drastically reduced their sport. One interviewee could not walk without being breathless. Another had to reduce his physical activity because of his joint pain. This is the most burdensome impact of a participant: that he is not as mobile as before.

Two patients (20%) had explained that they are not able any more to do alone the daily tasks. For instead: “*C’est que je ne suis plus capable de faire mes courses toute seule. J’ai toujours besoin d’un de mes enfants avec moi. À cause de la fatigue, je ne sais plus prendre des packs de coca, des packs d’eau et les mettre dans le caddie, du caddie de les mettre dans le coffre, d’arriver ici et de vider ma voiture...*” (04-02; F 46yo) Doing the dishes or cleaning could also be a quite intense labour for them.

Finally, a patient had reported another most burdensome physical impact: scars. According to him: *“Le plus gros impact de la maladie c’est que j’ai des grosses cicatrices sur le ventre qui me rappellent tous les jours que je suis malade.”* (04-05 ; M 26yo).

#### 4.2.4.3. Travel

Crohn’s disease had an impact on the life of three patients interviewed (n=3; 30%). Since the diagnosis of their disease, they favoured to travel in Europe, because it is closer to their home.

Taking planes could be challenging for patients taking immunosuppressants. Indeed, because these substances are dangerous, they need specific documents and protection to take it in the plane. Lastly, patients are frightened to travel in some countries, because they did not trust in their healthcare system or because eating the food could be risky for them.

#### 4.2.4.4. Sleeping disorders

Sleeping disorders were experienced by four patients interviewed (n=4; 40%). They have trouble to fall asleep, have insomnia or wake up sweaty in the middle of the night. They already had insomnia before, but the frequency of them increased since their diagnosis.

#### 4.2.4.5. Work/School

The impact on the work or on the study was widely reported among interviewees (n=9; 90%), and was the most burdensome impact, according to two participants.

Because of the symptoms of their disease, three participants (n=3; 30%) had to quit their work for several months or years. Since they all came back to work. But among all the patients interviewed, five had to change their work and three had to continue working part-time (n=3; 30%). They had to find less stressful work or with more adapted work schedule.

In this study population, three patients are still studying. All the three patients shared that Crohn’s disease had impacted their studies: their success and their orientation. An interviewee had been hospitalised during few weeks before his school exams. To finish his studies, he had to find an agreement with his professors to spread his program. And another patient had decided to become a nurse. However, at the beginning of his studies, his gastroenterologist discouraged him from becoming a nurse, because he is immunodeficient, cause of his treatment. Despite this advice, he decided to do this study and, in the future, he must choose his department carefully.

#### 4.2.4.6. Social impacts

Crohn’s disease also had an impact on patients’ family (n=4; 40%) and friends (n=4; 40%). Patients interviewed try to decrease as much as possible the impact of their disease on their social life. Three major impacts have been reported: family and friends had to adapt to the new dietary of the patients, people in their environment did not well understand the Crohn’s disease and the impact on the patient’s life and the eyes of the others had changed.

So, because of their fatigue, an attack, or an appointment with physicians, patients had to cancel their activities. But Crohn's disease is an "invisible disability". So, people, even patients' friends, generally are not aware of all the adaptation needed for the well-being of the patients.

Change in the eyes of the other was the most burdensome impact for three other interviewees. These participants had lost friends or boyfriends because of their condition. Their environment can have too much compassion and sometimes pity for patients. Fortunately, patients also find huge support from their family and friends.

Finally, two participants reported considerations about founding their own family (n=2; 20%). Currently, there is no real evidence about the inheritance of this disease, but patients were frightened to transmit the disease to their child.

More, two women interviewed had experienced pregnancy with their Crohn's disease (n=2; 20%). Their experiences are quite different. The first patient had four children, and she experienced four pregnancies without any symptoms. And after her deliveries, her disease was still in remission. The other patient had experienced two pregnancies. As for the other patient, pregnancies went well. However, after the delivery, her symptoms amplified. She had to wait four years before being in remission and having her second child. Lastly, this patient had reported that she could not breastfeed her children because of her treatment. It is one of her biggest regrets.

#### 4.2.4.7. Diet

Since their diagnosis, eight participants had to change their diet (n=8; 80%). They had to find by themselves the right balance in their diet. Even if they have received advice from their physicians, each person reacts differently. They had to avoid food containing fibres (because of the risk of occlusion), irritating for the bowels and food that is small and round because it could cause an occlusion. Even if they know what they could not eat, participants afford a sprain to their diet, from time to time. But they could regret it after: they know that they could have diarrhoea and abdominal pain because of their sprain, or they have to follow a strict diet few days before and after to limit the reaction of their body.

However, two participants explained that they did not change their diet since the diagnosis of their disease. After all, few times a year they had strong diarrhoea attacks. They agreed that if they listened more to their physicians' advice, maybe they will avoid these attacks.

Besides a strict diet, participants had to avoid alcohol and cigarette consumption. Alcohol can trigger abdominal pain and diarrhoea to these patients. One explained that with social pressure, he consumed alcohol with friends in a bar. He had spent all the evening in the toilets of the bar.

Finally, two participants are smokers (n=2; 20%). Their physicians had recommended that they stopped smoking. One has tried to stop, but he was so stressed that the intensity and frequency of their attacks increased.

#### 4.2.4.8. Visits to the hospital

Going frequently to the hospital was reported as an impact by four participants (n=4; 40%). According to three patients, the most burdensome impact of this disease is that they have to go

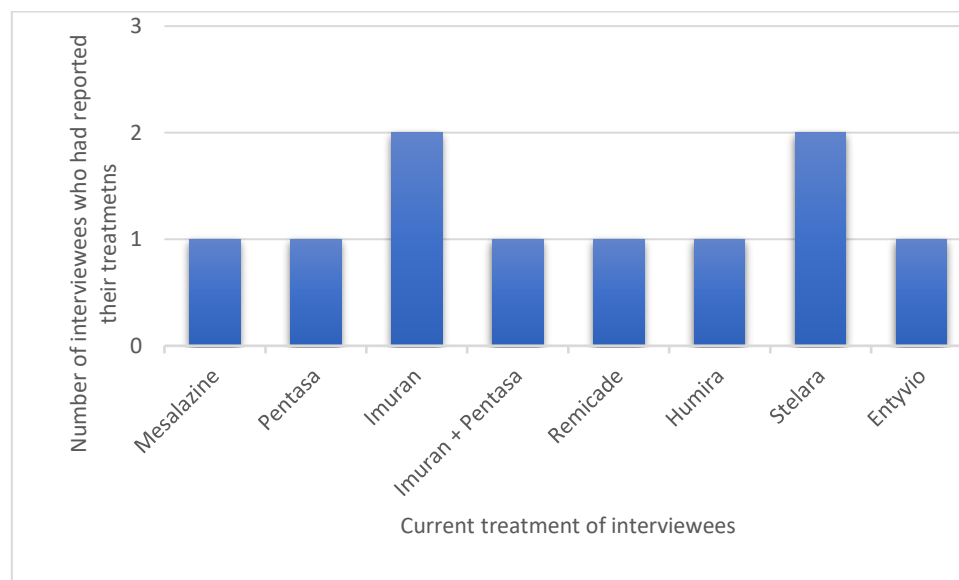
frequently to the hospital for examinations, for their treatments, or to see their gastroenterologist. *“J’ai été diagnostiquée quand j’avais 20 ans. Et donc à 20 ans on m’a posé l’étiquette “malade” sur la tronche. Mais je n’ai jamais été dans les hôpitaux, je n’ai jamais été opéré, jamais eu une intervention. Et mon quotidien d’un coup c’est devenu : il faut aller à l’hôpital une fois par mois, il faut faire une prise de sang une fois par mois, il faut aller voir l’infirmière une fois par mois, et d’un coup je dois avoir une quantité de médecins... Je ne suis pas habitué à ça. Ça a été un choc et ça a été super dur à vivre.”* (04-01; F 24yo) During their visits to the hospital, they have to do a lot of examinations that could be degrading or humiliating. Also, as written previously, these examinations can be a source of anxiety for the patients.

All these visits, examinations and treatment had a cost that impact the patients’ lives (n=4; 40%). Sometimes, all the treatment or examinations are not reimbursed by the health mutual. For instead, a participant needed fifty-two injections of Humira per year. However, the health mutual reimbursed only thirty-two injections per years. This injection cost eight hundred euros. Patients had to find arrangements to get their medication: they enter in clinical trial, gastroenterologists give them some extra injections, etc.

#### 4.2.5. Treatments of Crohn’s disease

Finding the right treatment could be a long journey for the patient. Often patients had to try several medications before finding the one that works for them. The figure 10 represents current treatment taken by the ten participants of the face-to-face patients’ interview.

As explained in the introduction, there are several classifications of treatments: corticosteroids, salicylic derivatives, immunosuppressants, biological and surgery.



**Figure 10: Current treatments taken by participants during the face-to-face interview**

First treatment of the patients interviewed were generally corticosteroids, such as cortisone, Medrol or Entocort. Symptoms of the disease stopped rapidly with these treatments. However, patients had reported a lot of side effects and they preferred to change it. Side effects

experienced by participants included bloating, weight gain, marks on the skins, fainting, heart palpitation, extrasystoles, etc.

Then, salicylic derivatives such as Mesalazine or Pentasa could be given to the patient. A participant had taken Mesalazine for forty years. With this treatment, their symptoms significantly decreased: he is in remission. The patient had only one side effect: gastric acidity.

Thereafter, immunosuppressants such as Imuran are prescribed to the participant. Imuran is tablets of immunosuppressants. First, a patient categorically refused it, because there is a risk to have a skin cancer. One of the four participants who have taken Imuran, three of them are satisfied: two are in remission and the other had to do more tests to evaluate the progression of his disease. The last patient had to change his treatment. Side effects reported by the participants are skin disorders (burns and warts), memory loss, the urge to urinate and patients are more vulnerable to the virus, so they catch more easily cold. A patient explained that to be less vulnerable to the virus, his general practitioner had vaccinated him against most frequent disease: flu, pneumonia, etc.

After, among biological prescribed to the patient, Remicade (Infliximab), Humira (Adalimumab), Stelara (Ustekinumab) or Entyvio (Vedolizumab) can be found. An interviewee had done an anaphylactic shock at the hospital during his first intravenous injection of Remicade: he suffocated and his face becomes very red. Another participant is treated with Remicade and is currently in remission. However, this treatment has few side effects: he continuously has a cold and often has skin infection such as pimples on his whole body.

Humira is given by injection to the patients. The number of injections depends on the severity of the disease. A participant had badly reacted to the injection of Humira: he was so exhausted that he fell asleep everywhere, in the middle of the day. He began to have huge joint pain in the back and in the knees. This treatment had triggered skin disorders: pimples and abscesses. He had to be operated to remove abscesses. Another patient is taking Humira and reacts well to this biological. He reported only two side effects: his articulations crunched and he has a pale skin.

Stelara (n=2) is also an immunosuppressant given by injection, generally prescribed for rheumatism and skin disorders such as psoriasis. This treatment is currently tested in clinical trial for the Crohn's disease. For this reason, patients received injections from the pharmaceutical firm in exchange for stool samples. Currently, this treatment is efficient for one of the two patients who are taking this medication. For the second, this treatment worked the first six months. But with time, the participant began to report few side effects: heart palpitations, dehydrated skin, hair loss, fainting, his fatigue increased and he suffered more from virus infection (cold, flu, angina, etc.). And he shared his fear because it is an experimental treatment for this condition. So, there is no sufficient hindsight. Because of the side effects and because the treatment is still experimental, this patient had decided to take less frequently is medication, waiting for another treatment.

Entyvio is an immunosuppressant given intravenously at the hospital. Only one interviewee is taking this medication. Even if he feels that his symptoms decreased, he had to go to the hospital to do more tests to determine if it is efficient. He had reported only one side effect: joint pain.



Patients also take a complement medication to decrease their abdominal pain when there have attacks, such as Dafalgan, Buscopan or Spasmomem. And patients tempt to decrease their stress. For instead, a participant is taken every day MetaRelax for two years to reduce his stress. Since he had no attack.

Finally, to treat their symptoms, four participants had to be operated: one for abscess, another for fistulas, and the last two for occlusions. One participant had to undergo two resection surgery due to his occlusions. Because of the resection surgery, he suffers from short bowel syndrome. His transit is accelerated and some nutrients are less absorbed. However, he is taking Questran to decelerate his digestion. For him, Questran is the most important treatment. Once, this medication was in stock shortage for three weeks. During all this time, he could do anything, because he had to go to the toilet ten to fifteen times a day.

## **5. Conclusions and perspectives**

Both qualitative methods, social media research and patients' face-to-face interview, allow a better understanding of Crohn's disease experience, from the patient perspective. All relevant information was classified into three categories: symptoms/signs, impacts on the patients' lives and treatments.

### 5.1. Number of concepts (primary objective)

The primary objective of this pilot study is to compare the reliability, validity and relevance of the data collected through patient face-to-face interviews versus social media research to determine if social media research allows to validly capture relevant patients' information in a Crohn's disease population. More specifically, the number of concepts (i.e., symptoms, impacts and treatment burden) and the level of detail used to describe each concept (e.g. duration, frequency and severity of symptoms) will be assessed for both methods.

Social media had reported a total of 29 concepts, including 14 symptoms, 4 signs, 6 impacts, 5 treatment-related concepts. Patients interviewed had reported a total of 35 concepts, including 20 symptoms, 6 signs, 8 impacts, 6 treatment-related concepts.

#### 5.1.1. Symptoms/Signs of Crohn's disease

##### 5.1.1.1. Gastrointestinal symptoms

A comparison of the GI symptoms reported by patients through the two data collection methods was summarised in the Table 6.

In the two methods, the main GI symptoms of Crohn's disease were reported: abdominal pain, diarrhoea, nausea and vomiting, bowel movement urgency and blood in the stools.

There is often an overlap in the information collected through both methods, for instead regarding how patients explained the frequency, duration and intensity of their abdominal pain. But the information collected can also be complementary. Let us take the example of the nausea. In social media research, it was explained that nausea can be a consequence of repetitive overwhelming abdominal pain. However, users do not explain clearly the frequency of their nausea. This information is retrieved in the patients' face-to-face interview.

Then, some minor symptoms are only cited and not explained. Sometimes, it appears that an explanation can be found in the other qualitative method. This is the case for the "blood in the stools" symptom: it has been explained by patients during interviews and not by social media users.

Also, one topic has been signalled by social media users and not by the patients interviewed: flatulence. And two new GI symptoms had been reported in the patients' face-to-face interview: constipation and belly bloating.

**Table 6: Summary of the GI symptoms reported in both methods: social media research and the patients' face-to-face interview.**

Symptoms	Social Media Research	% SMR	Patients' face-to-face interview	% Int
Abdominal pain	Variation in the intensity and duration	62%	-Compared to contraction or pain experienced during periods -Localised pain -Accompanied by spasms	100%
Diarrhoea	More often in the day-to-day life	62%	-Literally "empty themselves" -High at the beginning of the disease (a dozen times) -Followed by periods of constipation	100%
Bowel movement urgency	Could happen anytime, anywhere	22%	-Feel an urgent need, but do not have to go to toilets -Could happen anytime, anywhere	50%
Daily/Night frequency	-Could go to twelve times a day and eight times a night. -Have to go more frequently to the toilets than before the apparition of their disease	15%	Have to go more frequently to the toilets than before the apparition of their disease	20%
Nausea	Nausea can be a consequence of repetitive overwhelming abdominal pain	18%	-Very frequent for a patient -Two to three times a year for another patient	30%
Vomiting	Sometimes associated with nausea	11%	Family and friends thought the participant was bulimic	40%
Blood in the stools	No explanation	4%	Explained by the presence of haemorrhoids	40%
Flatulence	No explanation	4%	Not reported	0%
Constipation	Not reported	0%	Followed by periods of diarrhoea	30%
Belly bloating	Not reported	0%	No explanation	10%

#### 5.1.1.2. Non-gastrointestinal symptoms

A comparison of the non-GI symptoms reported through the two data collection methods was summarised in the Table 7.

Most of the non-GI symptoms have been reported in both methods: fatigue, weight change, malnutrition, lack of appetite, articular pain and fever. As for the GI symptoms, there are some overlapping in the information collected in the two methods. Time to time, the two methods are also complementary.

Regarding the number of themes reported, patients interviewed had spoken about more non-GI symptoms than social media users. Indeed, they have reported those symptoms related to their Crohn's disease: dehydrated skins, hair loss, eyes sensitive to the light and ORL disorders. Nevertheless, one social media user was the only patient to report an erythema nodosum as a symptom of his condition.

**Table 7: Summary of the non-GI symptoms reported in both methods**

Symptoms	Social Media Research	% SMR	Patients' face-to-face interview	% Int
Fatigue	-Have to rest when they can -Associated with weakness	56%	-Difficulties to recover -One patient: fainting -Causes? Treatment, malnutrition, lack of appetite or weight loss?	80%
Weight change	Weight loss reported for some users	37%	-Eight patients: weight loss -One patient: weight gain	90%
Malnutrition	Control their hydration and level of vitamin	11%	Deficiency in vitamin B12	30%
Lack of appetite	Not explained	11%	Body physically refused to eat	30%
Joint pain	One user: weak articulations	15%	-In ankles, knees, hips, hands, wrists or back. -Articulations are rigid: as elderly	50%
Fever	Until 40°C, for weeks	18%	Around 40°C	20%
Erythema nodosum	Not explained	4%	Not reported	0%
Fainting	Not reported	0%	Patient was too exhausted	10%
Dehydrated skins	Not reported	0%	No explanation	20%
Hair loss	Not reported	0%	No explanation	10%
Eyes sensitive to the light	Not reported	0%	No explanation	10%
ORL disorders	Not reported	0%	Demineralised teeth and burned sinuses (sinusitis)	10%

### 5.1.1.3. Signs

During this qualitative research, signs of Crohn's disease were also reported by patients. Those signs reported by social media users and participants of interviews were also compared. This comparison has been summarised in the table below (Table 8).

Three signs have been shared in both qualitative methods: inflammation, occlusion and abscesses. However, patients explained only signs about haemorrhoids, fistula and diverticula during patients' face-to-face interviews. And intestine lesions were only reported on social media.

In both methods, signs of the disease were reported by the patients but was not explained in detail. Some signs, such as diverticula or fistula, were reported with symptoms by the patients during interviews.

**Table 8: Summary of the signs reported in both methods**

<b>Signs</b>	<b>Social Media Research</b>	<b>% SMR</b>	<b>Patients' face-to-face interview</b>	<b>% Int</b>
Inflammation	-Associated with abdominal pain -Blood samples: high level of markers of inflammation	26%	Localised pain where the inflammation is higher	30%
Occlusion	-Associated with abdominal pain -Temporary stoma to treat it	11%	Patients had to be operated to treat their occlusions	20%
Abscesses	Anal and internal	18%	No explanation	10%
Intestine lesion	In the colon or in the anus	7%	Not reported	0%
Haemorrhoids	Not reported	0%	-Cause the presence of blood in the stools -Become marisca if not treated well	20%
Fistula	Not reported	0%	No explanation	20%
Diverticula	Not reported	0%	No explanation	10%

### 5.1.2. Impacts of Crohn's disease

After the symptoms/signs of Crohn's disease, the number of relevant information regarding the impacts of the disease had been summarised in the table 9, to compare them.

Impacts have been classified in eight categories and six of them are common for the two methods: emotional impacts, physical impacts, travel, work or school, social impacts and impacts about patients' nutrition. But in patients' interview, two additional categories emerged: sleeping disorders and frequency of the visits to the hospital.

Also, social media users have generally focused their discussions on the impacts of the disease on their life. One of the social media studied was organised with small testimonies of patients. Each testimony had a title. Most of the titles were related to an impact of their condition on their life. Here are few examples: "My environment was a real support to me", "I was really ashamed" or "I want to work again".

During the interview, most of the participants, especially those who are in remission, explained that their disease has currently little impact on their life. Also, they ensure that the disease had no impact on their life: they want to live their life normally. So, most of the impact reported by interviewees was experienced during two different periods of their life: at the beginning of their disease or when their treatments were not efficient.

**Table 9: Summary of the impacts reported in both methods.**

<b>Impacts</b>	<b>Social Media Research</b>	<b>Patients' face-to-face interview</b>
Emotional	-Anxiety: (33%) <ul style="list-style-type: none"> <li>• disease and treatments</li> <li>• their future</li> <li>• eyes of others</li> </ul> -Embarrassment (18%) -Feeling deeply down (15%) -Body changing (7%) -Feeling injustice (4%)	-Anxiety: (50%) <ul style="list-style-type: none"> <li>• disease and medical examination</li> <li>• possibility of treatment</li> </ul> -Embarrassment (50%) -Higher sensitivity (40%) -Feeling deeply down (40%) and depressed (10%) -Body changing (10%) -Less self-confidence (10%)
Physical	-Energise them: increased well-being and decreased stress -Reduced their physical activities -Few are not able anymore to practise sport	-Practice regularly sport (60%) -Reduced drastically it (40%) and two of them cannot do daily tasks (20%) -Presence of scars (20%)
Travel	Travelling: not all destinations (26%)	Travelling (30%): close to their home and not all the destination
Sleeping disorders	Not reported	Concerning 4 patients (40%): <ul style="list-style-type: none"> <li>• Trouble to fall asleep</li> <li>• Insomnia</li> <li>• Wake up sweaty in the middle of the night.</li> </ul>
Work/study	-Change it/work part-time (33%) -Had to leave work (15%)	-Change it/work part-time (30%) -Had to leave work (30%)
Social	-Family/friends: (very supportive but often not accept the disease -Pregnancy: (22%) <ul style="list-style-type: none"> <li>• had to be in remission</li> <li>• frightened about inheritance</li> <li>• symptoms reappeared at three-month pregnancy</li> </ul>	-Family/friends: no real impact except for one patient: pity of some friends (10%) -Pregnancy: (40%) <ul style="list-style-type: none"> <li>• Frightened about inheritance</li> <li>• No symptoms during pregnancy but a lot after</li> </ul>
Diet	-Finding empirically their own dietary (44%) -Few users: dietitian - Avoiding alcohol and cigarettes	-Avoiding fibres, food irritating, and small and round food (80%) -Accompanied by their gastroenterologists -Avoiding alcohol and cigarettes
Visits to the hospital	Not reported	-Before disease: do not use to go to the hospital (40%) -Costs linked to the examination and treatments (40%)

### 5.1.3. Treatments of Crohn's disease

Finally, the last analysed concept was the treatment. As for the symptoms and the impacts, a summary of the information about treatments of Crohn's disease, has been done (Table 10).

**Table 10: Summary of the treatments reported in both methods.**

<b>Treatments</b>	<b>Social Media Research</b>	<b>Patient's face-to-face interview</b>
Satisfaction	-Long journey to find efficient treatment -Most of them have their symptoms decreased	-Long journey to find efficient treatment -Seven patients in remission
Side effects	Treatment was not always explained: side effects reported for unknown treatment	Side effects reported for a known treatment
Operation	Ten users: for occlusion, abscesses, or to reduce symptoms via resection surgery	Four patients: for abscesses, fistulas, and occlusions
Hospitalisation	Eleven users for a short or long time	Six patients for a short or long time
Adherence	One patient: when feel better, take it less regularly	One patient: stock shortage
Vaccine	Not reported	One patient: need vaccines in complement with his treatment

Finding the efficient treatment can be quite a long intensive journey for patients, as explained in both qualitative methods. Among the ten patients interviewed, seven was in remission. Unfortunately, this kind of information is not found on social media. Users are speaking about a decreased of the severity and frequency of their symptoms, but not about remission.

During the interviews, participants had the opportunity to deeply explain the evolution of their disease and treatments. Also, each side effect reported being associated to a medication. In social media, users rarely named their treatment and no side effect reported being associated with the name of a treatment.

To conclude with the number of relevant information, it appears that main information is reported through the two methods. Nevertheless, the number of concepts reported during face-to-face interviews is higher (even if the sample size is smaller) than the number of concepts reported by social media users.

Symptoms of Crohn's disease were generally less frequently reported by social media users than by patients interviewed. For instead, 100% of patients interviewed had reported abdominal pain and diarrhoea, but only 62% of social media users had reported them. Also, the 50% of the interviewees had reported joint pain against one patient (4%) in social media. However, in the two qualitative methods, the content is generated differently. On social media, this is the users who decided the topics of their discussion. It is possible that other users experienced abdominal pain, diarrhoea or joint pain, but they had decided not to write about it online. During face-to-face interviews, interviewer followed the same interview guide for each participant. Thanks to this, researcher knows exactly how many patients experienced symptoms (or impacts or treatments) of the disease.

For the impacts and the treatments, this is quite different. Users shared more information about the impact of their disease on their life. The situation is exactly the opposite for the treatment: interviewees better explained to them.

## 5.2. Level of detail

Now that the number of relevant information has been assessed for each category, the level of detail will be discussed for both methods. Indeed, for the three concepts analysed, explanation and details were very different from one method to the other.

In social media, users are much more focused on the impact on their disease than on the symptoms or treatments. So that, the level of detail is high for the impacts than for the other concepts. For instead, users had frequently listed a certain number of symptoms without any explanation concerning the duration, the frequency or the severity. Also, as written before, information about treatment is not well explained by the users: a lot of information is missing.

Then, the most important advantage of the face-to-face interview is that more precision, explanation or details can be asked to the participants. Indeed, the interview guide was written to obtain all the information needed to answer the research question. So, for example, for each symptom, frequency had been asked to the participants.

Also, a majority of social media users had reported what they are currently experiencing. This allows having a fixed image of their disease. In contrast, all the patients interviewed had explained what they are experiencing from their diagnosis until the interview. This allows having an overview of what they had experienced or of the evolution of Crohn's disease and how they had to manage their life with Crohn's disease.

Lastly, social media users choose to speak about some thematic. They explained what is the most important, according to them. However, they did not explain in detail all the concepts mentioned. This also means that there is much more noise in texts written online by patients than in the transcripts of patients' interview. Indeed, the interview follows the same structure for each participant, dictated by the interview guide. Because there was less noise in the transcript of the patients' interview, the analysis was easier and faster.

## 5.3. Language used

The major difference between the two methods is that some patients interviewed were embarrassed to speak about their symptoms. They found some roundabout means to speak about diarrhoea. For instead, they have used the term: "digestive disorders". Nevertheless, after a few minutes, participants relaxed and described more freely their symptoms. In social media research, the term "diarrhoea" was always used by users.

Also, on social media chosen for this study, most of the patients' experience is shared in the form of testimonies. Because of it, every thought is well constructed by the patient, every word is well chosen. On the opposite, in the interviews, participants sometimes searched their words to formulate what they had in mind. Their stories were not all the time told fluently and were more spontaneous.

Finally, textual and verbal clues were analysed. In social media research, there were too few textual clues. Sometimes, suspension points were used when patients were annoying about some situations, or when they are facing new challenges. In social media where patient can reply to each other, some smiley was used. Generally, they were used to support other patients.



More, the verbal clues also helped to have a better understanding of the content. In the tone of the voice, different emotions can be detected. Sometimes, irony, laughing, or sadness had been detected in the patient's voice.

#### 5.4. Study population

For the patient face-to-face interviews, the population participating in the study is well known. Ten patients have been participating in this research: two men and eight women aged from 22 to 63 years old. During the patients' recruitment, more than ten women accepted to participate in the study, but only two men agreed to be interviewed. However, only ten participants had to be recruited for this research. To avoid too much bias linked to the gender of the participants, two men and eight women had been selected.

During the patients' recruitment, more than ten women accepted to participate in the study, but only two men agreed to be interviewed. However, only ten participants had to be recruited for this research. To avoid too much bias linked to the gender of the participants, two men and eight women had been selected. Why such a difference between men and women in the willingness of the participation in an interview? An explanation could be that more women are diagnosed with Crohn's disease than men. The sex ratio is equal to 1,3. So, for a man diagnosed with this condition, 1,3 women are also diagnosed (Observatoire national des MICI, 2015).

In social media research, population is not well known. As said before, anonymous texts or pseudonyms are frequent on the Internet and fake profiles can be hidden behind them. Nevertheless, to compare the sample size of both methods, two assumptions have to be done. The first assumption is that every user is diagnosed with Crohn's disease. And the second is that one patient did not register using two different profile names.

In all platforms, patients shared their testimony and their experiences of their disease. In each social media, patients' name is written above their testimony. However, in one platform, it is possible to answer anonymously to the patient's testimony. For this sample, among social media users, there were seven men and seventeen women, exclusive of the sixteen pseudonymous social media users who had answered other testimonies. Participants' aged is known only for one of the three platforms.

Unfortunately, health and demographic patients' information between the two populations have not been compared in our study. Indeed, as written above, only information about patients who have participated in interviews are available.

A last comparison about the sample size of the comparison of these two methods can be done. In face-to-face patients' interview, the concept of saturation is generally used to determine the sample size. For social media research, saturation could be used. But there is a huge limitation with this: the number of social media is not infinite. It is possible that saturation is never reached with social media research.

### 5.5. Time

Lastly, the time dedicated to both methods had been analysed. Is it true that interviewing patients takes a lot of time? It needs time to write the protocol and the interview guide, to recruit a sufficient number of patients, to interview each patient one after the others, and finally to analyse all the data collected. For the social media research, a protocol must also be written to determine the objectives of the study, social media must be chosen in a large range of possibilities and then analysed.

It appears that social media research is indeed less time consuming than the patient's face-to-face interviews. For both methods, a study protocol was written, explaining the whole study with the comparison of both methods. All the documents were sent to the same ethical committee.

Then, for the social media research, the selection of the platforms had taken approximately a day. Permission of the website was checked to ensure the content we are interested in can be assessed and collected. All the content was extracted and exported in three separated Word documents, one for each social media, to be analysed. And all the data were anonymized. This extraction and the analysis of the content with ATLAS.ti took almost a week.

For the patient face-to-face interview, as soon as the ethical committee approved the study, GP and patients' association were contacted. The first patient was interviewed eight days after the approval, but the last patient was interviewed more than two months after the first participants. Also, transcription of the interviews takes a lot of time: approximately one hour for ten minutes of interviews. During the transcription, data were anonymized. Then, the analysis of the interviews' content with ATLAS.ti took approximately a week.

To conclude with the time taken, in this study, the content analysis takes approximately the same times for both methods. However, it is the collection of data and the preparation of transcripts that take more times. With social media research, more or less two months can be gained.

### 5.6. Perspectives

To conclude this research, here are few perspectives. Social media research is a new approach proposed by the FDA (2019) to collect qualitative data. So, there is not yet a lot of evidence of the method's validity and reliability. Additional research, on other conditions, should be done to validate or not this new qualitative method. Also, it could be interesting to do a statistical analysis of these additional research. For instead, "Graph theory" could be used as a statistical analysis for qualitative research. This theory is defined by Tiernye (2012) as a study of graphs and how graphs could be used to understand complex problems. Thanks to this method, the relationship within the data is easily visualised and the strength of relationship between codes is calculated (Tiernye, 2012).

This research (summarise in the Table 11) allows determining that in social media research, data collected are correct and relevant. Nevertheless, face-to-face interview allows collecting more specific, detailed and comprehensive information than social media. Also, each method has their limitations.

**Table 11: Summary of the comparison between the two qualitative methods**

	Social media research	Face-to-face interview
Number of concepts	29 concepts: <ul style="list-style-type: none"><li>- 14 symptoms</li><li>- 4 signs</li><li>- 6 impacts</li><li>- 5 treatment-related concepts</li></ul>	35 concepts <ul style="list-style-type: none"><li>- 20 symptoms</li><li>- 6 signs</li><li>- 8 impacts</li><li>- 6 treatment-related concepts.</li></ul>
Level of detail	<ul style="list-style-type: none"><li>-Missing information/explanation (symptoms or treatment)</li><li>-Explanation about what they are currently experiencing</li></ul>	<ul style="list-style-type: none"><li>-More details or precision can be asked</li><li>-Explanation of what they are living since the beginning of their disease</li></ul>
Language used	<ul style="list-style-type: none"><li>-have always used the term “diarrhoea”</li><li>-Though well constructed</li><li>-Too few textual clues</li></ul>	<ul style="list-style-type: none"><li>-Embarrassed to speak about some symptoms (“small accidents”, “digestive disorders”, etc.)</li><li>-Stories not fluent but spontaneous</li><li>-Verbal clues: detecting emotion in patient’s voice</li></ul>
Study population	<ul style="list-style-type: none"><li>-No health and demographic information</li><li>-No saturation</li></ul>	<ul style="list-style-type: none"><li>Health and demographic information</li><li>-Saturation</li></ul>
Time	Less time consuming	Time consuming

Social media research is less time consuming. A consequent number of relevant information was reported, especially about symptoms and impacts of the disease. However, some details could be missing in the messages written by social media users. Because of it, the research question could not be properly answered. Noise is more present in patients’ testimonies on social media because users had chosen what they want to write online. Information is not following the same structure as for patients’ face-to-face interview, thanks to the interview guide.

On the other hand, even if patients’ face-to-face interview is more time consuming, this method allows collecting information easily that will answer the research question, thanks to the interview guide. But participants can be embarrassed of speaking about their disease. It is important that interviewer gives them confidence all along the interview.

So, depending on the time, the funding, the target population or the research question, social media research could be used as a qualitative method to collect data. For instead, social media research could be enough to guide research questions about a global understanding of the disease burden or treatment expectation. Regarding the PRO-development, social media research is not enough. Indeed, the specificity of each concept is very important to define the trial endpoint, in the PRO-development. There, face-to-face patient’s interview will be a more appropriate qualitative method.

Finally, learning qualitative methods in the courses of biomedical sciences can be useful. Such methods allow targeting research that is useful for patients or bringing researchers concrete objectives to improve quality of life of patients. However, interviews or discourse analysis is too few developed in biomedical courses but can be a great learning for the future career of biomedical students.

## **6. Acknowledgments**

I am grateful to my supervisors, Prof. Laure Delbecque and Prof. Martin Desseilles, for their useful feedback, comments and engagement through the learning process that was this master thesis. They were precious guide through this master thesis.

I would also like to thank the department of psychology of University of Namur to welcome me, during all my research.

Then, I would like to thank Mr. Jean-Pierre Gillet, Prof. at the University of Namur, to coordinate this master thesis and its defence.

More, I would like to express my gratitude to the ten participants of the face-to-face interview, who have taken their precious time to answer all my questions. Sometimes, it was not easy for them to speak about their condition, but they had shown their willingness to share their experiences about it.

Finally, I want to thank my family, Virgile my boyfriend and my friends to support me during this long journey.

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## Annexe 1: Case Report From (CRF)

### 1) Critères d'inclusion

Les sujets qui répondent aux critères suivants pourront être inclus dans l'étude. Le sujet répond-il aux critères requis pour l'inclusion à l'étude ?	Oui	Non
Le sujet a entre 18 et 75 ans		
Le sujet a été diagnostiqué de la maladie de Crohn, il y a au moins 12 mois		
Le sujet est capable de comprendre et de signer volontaire le formulaire de consentement éclairé et de participer à un interview		

### 2) Critère d'exclusion

Le critère suivant exclura les sujets potentiels de l'étude.	Oui	Non
Le sujet souffre d'un trouble psychiatrique qui pourrait nuire à la qualité de l'interview.		
Le sujet souffre d'une maladie affectant le tube digestif autre que la maladie de Crohn (ex : colite ulcéreuse, abcès abdominaux, obstruction intestinale, syndrome de l'intestin irritable, etc.)		
Le sujet souffre d'un trouble inflammatoire autre que la maladie de Crohn (ex : polyarthrite rhumatoïde, psoriasis, ect.)		
Le sujet a eu une chirurgie abdominale dans les 6 derniers mois		

### 3) Admissibilité du sujet

Date de signature du consentement éclairé : ...../...../..... (JJ/MM/AAAA)
Le sujet répond-il à tous les critères d'inclusion/d'exclusion ? a. Oui b. Non

### 4) Participation à l'interview

Date de l'interview : ...../...../..... (JJ/MM/AAAA)
Durée de l'interview : .....

Commentaires de l'investigateur : .....  
.....  
.....

J'ai examiné les données de ce rapport et j'ai constaté qu'elles étaient complètes et exactes.  
(Signer et dater après la fin de la participation du sujet à l'étude)

.....  
Signature principal investigateur

.....  
Date (JJ/MM/AAAA)

## Annexe 2: Interview guide

Date de l'interview : \_\_\_\_/\_\_\_\_/\_\_\_\_

Heure de début : \_\_\_\_\_

Heure de fin : \_\_\_\_\_

Nom de l'interviewer : \_\_\_\_\_, \_\_\_\_\_

### VERSION HISTORY TABLE

Version	Date	Auteur(s)	Résumé des changements/Commentaires

## I. Conduites et procédure de l'interview (60 minutes):

Section	Aperçu	Durée
Introduction		
Symptômes		
Impact		
Conclusion		

### Notes pour l'interviewer :

- Les questions posées sont des questions ouvertes et sont posées dans le but d'obtenir des réponses spontanées de la part du patient.
- En vue d'obtenir des réponses spontanées, utiliser les termes “décrivez s'il vous plait” ou “comment ?”, quand cela est possible.
- Des questions supplémentaires ne sauront être utilisés seulement pour être sûr de bien comprendre la signification des explications du patient et pour être sûr que nous avons un rapport précis des réponses du patient.
- N'utiliser les questions supplémentaires que si le patient semble avoir des difficultés à s'exprimer, mais être sûr de bien donner suffisamment de temps au patient pour formuler ses pensées et répondre.
- Ce document a été développé en vue de guider l'interviewer tout au long de l'interview. Tu n'as pas besoin de l'utiliser comme script pour l'interview.
- Familiarise-toi avec ce guide, comme cela tu pourras obtenir des informations pertinentes à tous moments de l'interview.

## **SECTION 1 : Introduction (Approx. 5 minutes)**

*“Merci de prendre le temps de nous aider dans nos recherches. Mon nom est Isabelle Vandersteen. Je suis étudiante en Sciences Biomédicales à l’université de Namur. Pour mon mémoire. Il s’agit d’une étude visant à collecter des renseignements sur comment les patients vivent avec leurs maladies et/ou leurs traitements.*

*Cette étude est conduite en vue d’obtenir une meilleure compréhension des symptômes et des Impacts de la maladie de Crohn. Aucun médicament ou traitement ne sera donné durant cette étude.*

*L’interview d’aujourd’hui durera 60 minutes environ. Durant ce temps, je vais poser des questions par rapport à vos symptômes liés à la maladie de Crohn, leur fréquence et sévérité ; ainsi que la manière dont ils vont influencer votre vie.*

*Avant le début de l’interview, je voudrais vous demander la permission d’enregistrer cette interview, afin que je puisse être sûre de saisir avec précision ce que vous allez me dire ainsi que les informations que vous me fournirez, et afin que je puisse vous prêter une attention particulière au cours de l’interview. Si vous êtes d’accord que l’interview soit enregistrée, s’il vous plaît essayez de parler avec clarté et suffisamment fort afin que je puisse vous entendre sur l’enregistrement. Si vous choisissez de ne pas être enregistré, je vais prendre des notes, mais je pourrais vous demander de faire des pauses au cas où j’en aurais besoin pour saisir le plus de détails par rapport à ce que vous allez dire.*

*Avant le début de l’interview, Est-ce que j’ai votre permission pour enregistrer l’interview ?*

☐ *Oui*

☐ *Non*

*[Si oui, dire :] Merci. Je vais commencer maintenant l’enregistrement.”*

## **SECTION 2 : Symptômes (Approx. 15 minutes)**

**Objectif :** Fournir au patient l'occasion de décrire ses expériences avec ses symptômes de la maladie de Crohn.

*“Pouvez-vous décrire les symptômes de la maladie de Crohn?”*

Note pour l'interviewer : Pour chaque symptôme, utilise les questions supplémentaires suivantes :

- *PROBE: Pouvez-vous me décrire [Symptôme] ? Qu'est-ce que cela vous fait ? Où le ressentez-vous ?*
- *PROBE: Qu'est-ce qu'une bonne journée, avec votre [Symptôme] ? Qu'est-ce qu'une mauvaise journée, avec votre [Symptôme] ?*
- *PROBE: Quand est-ce que ce [Symptôme] a commencé? (avant le diagnostic, avec le traitement ?)*
- *PROBE: A quelle fréquence avez-vous [Symptôme] ?*
- *PROBE: Combien de temps dure [Symptôme] ?*
- *PROBE: [Symptôme] il y a-t-il un changement sur base quotidienne ou il y a-t-il des fluctuations au cours de la journée ?*
- *PROBE: Quelle est la sévérité de [Symptôme] ?*
- *PROBE: A quel point [Symptôme] est-il gênant pour vous ? De quelle manière ?*
- *PROBE: “Et quelle est selon vous, la cause du [Symptôme] ?”(Vérifier si le symptôme est attribué à la maladie de Crohn, au traitement ou à une autre raison (ex. Âge). Alors demander : “pourquoi pensez-vous cela ?”*
- *PROBE: Pouvez-vous comparer [Symptôme] avant et après le diagnostic de la maladie de Crohn? Dans quel sens est-il différent/similaire qu'avant ?*

*“Quels autres symptômes ressentez-vous actuellement ou avez-vous ressenti ?”*

Note pour l'interviewer : passer par les questions supplémentaires de la Q1, pour chaque symptôme que le patient mentionne spontanément. S'il n'est pas mentionné spontanément, passer aux questions suivantes :

Si pas mentionné spontanément :

- *Douleur abdominale*
- *Diarrhée chronique*
- *Perte de poids*
- *Fatigue*
- *Anorexie*
- *Saignements rectaux*
- *Présence de malnutrition*
- *Obstruction intestinale*

*“Quels symptômes sont-ils les plus gênant et pourquoi ?”*

### **SECTION 3 : IMPACTS (Approx. 15 minutes)**

**Objectif :** Fournir au patient l'occasion de décrire l'impact de la maladie de Crohn sur leur vie.

“Nous allons discuter de comment vous avez été affecté par votre maladie. Pouvez-vous me décrire comment vous avez été affecté” :

Note pour l'interviewer : Pour chaque domaine, demandé (si ce n'est pas mentionné) :

- PROBE: Pouvez-vous me décrire [Impact] ?
- PROBE: En y réfléchissant à [Impact], qu'est-ce qu'un mauvais jour et qu'est-ce qu'un bon jour pour vous ?
- PROBE: Quand est-ce que [Impact] a commencé (avant le diagnostic, avec le traitement, etc.) ?
- PROBE: A quelle fréquence ressentissiez-vous [Impact] ?
- PROBE: Quelle est la durée de [Impact]
- PROBE: Est-ce que [Impact] est constant (journée/semaine) ou fluctue-t-il durant la journée/semaine ?
- PROBE: Quelle est la sévérité de [Impact] ?
- PROBE: A quel point [Impact] est-il gênant pour vous ? De quelle manière ?
- PROBE: Et quelle est selon vous, la cause du [Impact] ?” (Vérifier si le symptôme est attribué à la maladie de Crohn, au traitement ou à une autre raison (ex. Âge). Alors demander : “pourquoi pensez-vous cela ?
- PROBE: Pouvez-vous comparer [Impact] avant et après le diagnostic de la maladie de Crohn? Dans quel sens est-il différent/similaire qu'avant ?

“Quelle partie de votre vie est affectée par la maladie de Crohn ?”

Note pour l'interviewer : passer par les questions supplémentaires de la Q1, pour chaque impact que le patient mentionne spontanément. S'il n'est pas mentionné spontanément, passer aux questions suivantes :

- PROBE: Physiquement et/ou votre capacité à faire des activités physiques
- PROBE: Avez-vous du mal à dormir ?
- PROBE: Activités quotidiennes?
- PROBE: Si d'application : responsabilités professionnelles ?
- PROBE: Activités sociales ?
- PROBE: Loisirs ?
- PROBE: Relation avec la famille ?
- PROBE: Relation avec les amis ?
- PROBE: Emotionnellement ?
- PROBE: Humeur (Dépression/ Anxiété/ Inquiétude/Embarrasement)

“Pouvez-vous me dire quelle(s) est/sont les parties de votre vie qui sont les plus affectée ? Pour quelles raisons ?”

#### **SECTION 4 : Traitements (approx. 15 min)**

**Objectif :** Fournir au patient l'occasion de décrire ses expériences avec les traitements de la maladie de Crohn.

“Nous allons discuter de comment vous avez été affecté par le traitement de votre maladie. Pouvez-vous me décrire si et comment vous avez été affecté” :

Note pour l'interviewer : Pour chaque domaine, demandé (si ce n'est pas mentionné) :

- *PROBE: Pouvez-vous me décrire [Expériences due au traitement] ?*
- *PROBE: En y réfléchissant à [Expériences due au traitement], qu'est-ce qu'un mauvais jour et qu'est-ce qu'un bon jour pour vous ?*
- *PROBE: Quand est-ce que [Expériences due au traitement] a commencé (avant le diagnostic, avec le traitement, etc.) ?*
- *PROBE: A quelle fréquence ressentissiez-vous [Expériences due au traitement] ?*
- *PROBE: Quelle est la durée de [Expériences due au traitement] ?*
- *PROBE: Est-ce que [Expériences due au traitement] est constant (journée/semaine) ou fluctue-t-il durant la journée/semaine ?*
- *PROBE: Quelle est la sévérité de [Expériences due au traitement] ?*
- *PROBE: A quel point [Expériences due au traitement] est-il gênant pour vous ? De quelle manière ?*
- *PROBE: Et quelle est selon vous, la cause du [Expériences due au traitement] ?” (Vérifier si le symptôme est attribué à la maladie de Crohn, au traitement ou à une autre raison (ex. Âge). Alors demander : “pourquoi pensez-vous cela ?*
- *PROBE: Pouvez-vous comparer [Expériences due au traitement] avant et après le diagnostic de la maladie de Crohn? Dans quel sens est-il différent/similaire qu'avant ?*



### Annexe 3: Coding Book

Code	Definition
<b>Descriptor</b>	
Descriptor::Duration	Used when the duration is expressed
Descriptor::frequency	Used when the frequency is expressed
Descriptor::Severity	Used when the severity is expressed
<b>Symptoms</b>	
Symptom::GI::Blood	Used when blood in the stools is reported
Symptom::GI::BellyBloating	Used when belly bloating is reported
Symptom::GI::Constipation	Used when constipation is reported
Symptom::GI::Daily/Night frequency	Used when daily or night frequency is reported
Symptom::GI::Diarrhoea	Used when diarrhoea is reported
Symptom::GI::Flatulence	Used when flatulence is reported
Symptom::GI::Nausea	Used when nausea is reported
Symptom::GI::Urgency	Used when bowel movement urgency is reported
Symptom::GI::Vomiting	Used when vomiting is reported
Symptom::DehydratedSkin	Used when dehydrated skin is reported
Symptom::Erythema	Used when erythema is reported
Symptom::EyesSensitive	Used when eyes sensitivity to the light is reported
Symptom::Fatigue	Used when fatigue is reported
Symptom::Fever	Used when fever is reported
Symptom::Fainting	Used when fainting is reported
Symptom::HairLoss	Used when hair loss is reported
Symptom::Lack Appetite	Used when lack of appetite is reported
Symptom::ORL	Used when ORL disorders is reported
Symptom::Pain::Abdominal	Used when abdominal pain is reported
Symptom::Pain::Joint	Used when joint pain is reported
Symptoms::Weight::Gain	Used when a gain weight is reported
Symptom::Weight::Loss	Used when a loss weight is reported
Symptom::Weight::Malnutrition	Used when malnutrition is reported
<b>Signs</b>	
Sign::Abscess	Used when abscess is reported
Sign::Diverticula	Used when diverticula are reported
Sign::Fistula	Used when fistula is reported
Sign:: Haemorrhoid	Used when haemorrhoid is reported
Sign::Inflammation	Used when inflammation is reported
Sign::IntestineLesion	Used when intestine lesion is reported
Sign::Occlusion	Used when occlusion is reported
<b>Impacts</b>	
Impact::Diet	Used when an impact on the diet is reported

Impact::Emotion::Anxiety	Used when anxiety is reported
Impact::Emotion::BodyChange	Used when an emotion about body change is reported
Impact::Emotion::Down	Used when period of emotional down is reported
Impact::Emotion::Embarrassment	Used when embarrassment is reported
Impact::Emotion::Injustice	Used when a feeling of injustice is reported
Impact::Emotion::SelfConfidence	Used when a decrease of self-confidence is reported
Impact::Sensitivity	Used when a higher sensitivity is reported
Impact:: Physical::Activities	Used when an impact about physical activities is reported
Impact::Physical::Scar	Used when scars are reported
Impact::Sleeping	Used when sleeping disorders is reported
Impact::Social::Family	Used when an impact about family is reported
Impact::Social::Friend	Used when an impact about friendship is reported
Impact::Social::Pregnancy	Used when an impact about founding a family or about pregnancy is reported
Impact::Social::Study	Used when an impact about work is reported
Impact::Social::Work	Used when an impact about study is reported
Impact::Travelling	Used when an impact on travelling is reported
Impact::VisitHospital::Frequency	Used when the frequency of visits to the hospital is reported
Impact::Cost	Used when costs regarding the treatment or the visits to the hospital are reported
<b>Treatments</b>	
Treatment::Adherence	Used when the adherence to the treatment is reported
Treatment::Hospitalization	Used when hospitalization is reported
Treatment::Operation	Used when operation is reported
Treatment::Satisfaction	Used when a satisfaction to the treatment is reported
Treatment::SideEffect	Used when side effect of a treatment is reported
Treatment::Vaccination	Used when need of vaccination is reported